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Mothers with a learning disability: their experiences of service
provision during the postnatal period

Suzanne Wilson

Doctorate in Clinical Psychology

The University of Edinburgh
August 2011

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Abstract

Introduction: There is growing evidence that many parents with learning disabilities, when given adequate support, can parent successfully. Childbirth is a significant life event that marks a woman's transition to motherhood and is a time when parents first learn to nurture their children. Postnatal care aims to facilitate this learning experience as well as promote the emotional and physical well-being of both infant and mother. To date, no research has explored the support mothers with learning disabilities receive during the postnatal period. To fill this gap in the research and help inform service provision, this study aims to explore how mothers with learning disabilities experience postnatal care.

Method: Semi-structured interviews were carried out with six mothers with learning disabilities. The data were collected and analysed using Interpretative Phenomenological Analysis.

Results: Mothers' experiences of postnatal care were conceptualised within four super-ordinate themes: challenges of providing support, how support was delivered, learning to cope and challenges to building trust. All of these had accompanying subthemes.

Discussion: The results are discussed in the context of relevant literature. Consistent with previous research which has been carried out with parents with learning disabilities, participants were found to be highly dependent on informal support. The participants acknowledged the value of professional input and their perceptions of how this support was delivered had important implications. Learning how to cope with the demands of their new role raised issues not dissimilar to those of parents without learning disabilities. Challenges, however, were faced in establishing trusting relationships with professionals. The findings

were found to have implications for clinical practice which are described and suggestions for future research made.

Conclusion: The findings suggest that participants' informal supports play a key role during the initial stages of parenthood particularly with providing practical support in areas which present challenges. Professional input was valued when delivered according to the typical pathway of care post-birth. It is recommended that consideration is given to how the support is delivered to participants. This should essentially seek to empower parents rather than undermine them as how support was perceived by parents impacted on their subsequent engagement with professionals.

1. Systematic review

*This review was prepared in accordance with guidelines for the journal **Research in Developmental Disabilities** (see Appendix 1)*

Abstract

The exact number of parents with an intellectual disability is unknown, but an increasing number are becoming known to health and social care services. Existing literature indicates that parents with an intellectual disability can learn parenting skills and that social support may be important in enabling them to adequately perform this role. This present paper reviewed two types of intervention for parents with intellectual disabilities: those designed to strengthen social relationships and those to teach parenting skills. A literature search was carried out for articles using a range of databases. A limited number of evaluative studies were found. The evidence for interventions aimed at strengthening social relationships was unclear. Although positive changes were observed in the studies, there were limitations in design which restricted the generalisability of the results. The evidence for parental skills teaching was encouraging and there was the suggestion that behavioural based interventions are more effective than less intensive forms such as lesson booklets and the provision of normal services. There were, however, a number of factors which may have biased the results and there is a need for further large scale controlled studies to provide clearer evidence. There is also a need to explore further additional factors relating to child, parent and family which may impact on outcomes.

1 Introduction

Parents with an intellectual disability represent one of the most vulnerable parenting groups in society, being at an increased risk of losing custody of their children (Booth & Booth, 2005). The exact number of parents with an intellectual disability in the UK is unknown with estimates varying widely from 23,000 to 250,000 (Department of Health & Department for Education and Skills, 2007). Regardless, practitioners in both health and social services report a growing number of referrals for this parenting population (Booth & Booth 2005; Genders, 1998; Woodhouse, Green & Davies, 2001). It is estimated that between 40-60% of parents with intellectual disabilities are unsuccessful in meeting the standard of “good enough parenting” and end up having their children removed (McConnell, Llewellyn & Ferronato, 2000). The majority of concerns regarding the children’s welfare relate to neglect or emotional abuse (Cleaver & Nicholson, 2005).

The problems that parents with an intellectual disability experience in providing adequate childcare can reflect limitations in cognitive ability (Feldman, Case & Sparks, 1992). This can include the ability to generalise information from one setting to another, to adapt strategies as the child develops and provide sufficient cognitive stimulation especially in the area of play (Morgan & Goff, 2004). Parents with intellectual disabilities have also demonstrated difficulty with expressing affection and interacting positively with their children in comparison to mothers in the general population (McGaw & Sturmey, 1994).

In addition to cognitive factors, the success of this group to parent effectively can be affected by factors relating to the parent, child, family and their environment. Mayes, Llewellyn, and McConnell (2006) found that expectant mothers with intellectual disabilities may have to contend with negative and oppositional attitudes to their pregnancy from family and professionals. As parents, they have more impoverished support networks (Kroese,

Hussein, Clifford & Ahmed, 2002) and are at greater risk of poverty and inadequate housing (Cleaver & Nicholson, 2005). Parents with intellectual disabilities also, as a group, report poorer mental and physical health than their peers (Aunos, Feldman & Goupil, 2008; O'Keefe & O'Hara, 2008). McGaw, Scully and Pritchard (2010) recently identified that parents with an intellectual disability who have been exposed to childhood trauma or who have a physical disability were at a higher risk of child protection concerns as were those who had a partner with a higher IQ or a child with special educational needs.

These contextual factors not only affect parenting ability, but also influence the outcome of interventions for parents with intellectual disabilities. Despite the tendency for this group to be over-represented in care proceedings, many can successfully parent given adequate support (Murphy & Feldman, 2002). Cleaver and Nicholson (2005) argue that the difficulty parents with intellectual disabilities have in providing sufficient childcare reflects a lack of parental education combined with the time-limited support of social care services. Recent UK policy reflects a drive to improve the support for these parents and to maximise the chances of their children being raised by them in a positive and supportive environment that appropriately meets their needs (Department of Health & Department for Education and Skills, 2007). Interventions for parents with an intellectual disability have developed in two main areas: teaching parenting skills and strengthening the social relationships of parents (International Association for the Scientific Study of Intellectual Disabilities [IASSID], 2008).

It has only been since the early 1980's that studies have been carried out evaluating the effectiveness of parenting skill interventions for parents with intellectual disabilities (Feldman, 1994). These include a focus on discrete skills such as improving grocery shopping and menu planning skills (Sarber, Halasz, Messmer, Bickett, & Lutzker, 1983), bathing,

changing nappies and cleaning baby bottles (Feldman et al. 1992). An early review of parental skills training by Feldman (1994) concluded that, when given appropriate training, parents with an intellectual disability could learn parenting skills. Feldman (1994) recommended that interventions use behavioural techniques such as task analysis, modelling, feedback and reinforcement and thereby adopt a performance rather than knowledge based approach. It was also recommended that training was situated within the home, or as home-like an environment as possible, to facilitate the generalisation of skills.

A later review by Wade, Llewellyn and Matthews (2008) concluded that, despite reasonable evidence for the effectiveness of skills teaching for parents with intellectual disabilities, few of the studies examined the generalisation of skills and the influence of contextual factors on the success or otherwise of an intervention. A more recent review of three parental skills training interventions found equivocal results, with only some parents demonstrating an improvement in parenting knowledge and skills (Coren, Hutchfield, Thomas & Gustafsson, 2010). The authors acknowledged the potential bias due to the small sample sizes involved and highlighted the need for more research in this area.

More recently, innovative approaches have been developed to enhance the social relationships of parents with intellectual disabilities through group based learning environments (Booth & Booth, 2003). Several studies have highlighted the impoverished support networks experienced by mothers with an intellectual disability compared with mothers in the general population (Kroese et al. 2002; Llewellyn & McConnell, 2002; Llewellyn, McConnell, Cant & Westbrook, 1999). Guinea (2001) found that mothers with an intellectual disability reported an average of 4-5 key people in their lives who typically fell into one of three relationship groupings: family, professionals or friends. Llewellyn and McConnell (2002) explored the support networks of parents with an intellectual disability.

They found that mothers living alone had more service centred networks whereas mothers living with a partner had more family centred networks with relatively dispersed family ties. In contrast, mothers living with a parent or parent-figure were found to have more local family based networks. Few mothers identified supportive ties with friends and neighbours. The authors concluded that mothers were isolated from their local communities and potentially vulnerable if support provided by families broke down. This sense of isolation from local communities has been highlighted first-hand by parents themselves. In a study looking at their perceptions of service needs, Llewellyn, McConnell and Bye (1998) found parents with intellectual disabilities expressed the need for help with community participation, including the opportunity to meet people and make friends.

Research with parents in the general population has demonstrated that social support can be an effective protective factor against negative affect (Koeske & Koeske, 1990). Kroese and colleagues (2002) suggested this may also apply to mothers with intellectual disabilities. They found that the larger and more helpful the support network of mothers, the better their psychological well-being. The authors concluded that social support seemed to affect parenting indirectly via its effects on psychological well-being.

In summary, it seems that interventions designed to teach parenting skills can help parents with intellectual disabilities and that social support may play a pivotal role in successfully performing this parenting role. The aim of this paper is to systematically review two types of interventions for parents with intellectual disabilities: those designed to strengthen social relationships and those developed to teach parenting skills.

2 Materials and methods

2.1 Inclusion and exclusion criteria

The review included papers which focused on interventions for parents with intellectual disabilities that provided quantitative outcome measures to judge the effectiveness of the intervention. Studies in the English language that were carried out internationally were included. Studies that had unclear or inadequate outcome measures or did not provide adequate descriptive information regarding the intervention were excluded. As reviews of earlier research in parental skills teaching have been previously carried out (e.g. Coren et al. 2010; Feldman, 1994; Wade et al. 2008) and given the wider scope of this review, the search excluded studies pre- 1999. A flowchart outlining the different stages of identifying studies for inclusion is shown in Fig 1 (See Appendix 2).

2.2 Search Strategy

A literature search was carried out using OVID databases including, psycINFO (from 1987), EMBASE (from 1980), ERIC (from 1965), Medline (without revisions from 1996) and MIDRIS. Searches were also carried out with the databases CINAHL (from 1937) and ASSIA (from 1987). The search included the terms “mothers” and “parents” combined with “intellectual disability(ies)”, “learning disability(ies)”, “learning difficulty(ies)”, and “mental retardation”. The search carried out in November 2010, produced 231 unpublished or published papers in the English language. Secondary searches were also conducted on references of key papers and this produced one paper (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003). After excluding reviews, theoretical or discussion papers and/or qualitative studies 27 papers remained. Those which were pre-1999 primarily descriptive and/or did not provide clear outcome measures were further excluded (e.g. Hames & Noble, 2009; Heinz &

Grant, 2003; Starke, 2010; Tarleton, 2008). The characteristics and results of the seven remaining studies are summarised in Table 1 (see Appendix 3).

2. 3 Quality indicator

The quality of each study in the present review was considered in reference to national recommendations (Scottish Intercollegiate Guidelines Network [SIGN] 2008). The SIGN study design algorithm (SIGN, 2008) (see Appendix 4) was adhered to and studies were classified as either randomised controlled trial (RCT), non-randomised controlled trial or before-after study/interrupted time series. The relevant checklist was then consulted according to the design of the study. The SIGN algorithm advises that no checklist should be applied to a before-after study/interrupted times series and that these studies should be considered less robust in terms of the evidence provided. The checklist for controlled trials included rating the extent to which the study addressed an appropriate and clear question, the use of standard, valid and reliable outcome measures, the rate of drop out before completion of the intervention, whether participants were analysed in the groups to which they were allocated and how participants were assigned to treatment groups. For studies adopting a RCT design, assessing the use of an adequate concealment method and whether participants and investigators were kept blind about treatment allocation, were also considered. On completion of this, the paper was awarded one of three possible codes reflecting how well the study had minimised the risk of bias. This indicated that either all or most of the criteria were met (++), that some of the criteria were met (+) or that few or none of the criteria were met (-). The quality rating of each study is outlined in Table 1 (See Appendix 3).

3 Results

Out of the seven studies reviewed, one was a RCT which suggested that a home based skills teaching programme was more effective than other less intensive forms of intervention in teaching parents how to manage home dangers, accidents and childhood illness (Llewellyn, McConnell, Honey, Mayes & Russo, 2003). Encouraging results were also found in other less controlled studies (Feldman & Case, 1999; Feldman, Ducharme & Case, 1999; McConnell, Dalziel, Llewellyn, Laidlaw & Hindmarsh, 2008; McGaw, Ball & Clark, 2002; Mildon, Wade & Matthews, 2008) whilst, for one study, it was less clear cut with not all outcome measures producing positive results (Brisson, 2010). The studies either examined the effectiveness of interventions targeting the social relationships of parents with intellectual disabilities or the teaching of child-care skills therefore these two areas will be reviewed individually.

3.1 Social relationships

McGaw et al. (2002) piloted a group intervention developed to enhance the self-concept of parents with an intellectual disability as well as the quality of their relationships with their children, partners, family members and professionals. The parents recruited for the study were part of a special parenting service in the UK and had an identified intellectual disability as well as being the main carer/s of their child residing with them. The format of the group was semi-structured and the curriculum adopted a cognitive behavioural therapy approach to teaching topics. To facilitate generalisation to the home situation, participants were given activities to complete at home each week between sessions. The study included a control group roughly equivalent in characteristics and adopted a between group repeated measures design. Both the control group (n=10) and the experimental group (n=12)

simultaneously received home-based teaching programmes. The average rate of attendance was 8.8 parents per week.

Three standardised outcome measures were employed at baseline, post-group and follow-up. The Judson Self-Rating Scale (Judson & Burden, 1980) was used to measure parent's self-concept as well as their feelings about their child, judgements about their child's capabilities and interactions with professionals and others. The Behaviour Problem Index (BPI; Cunningham, Sloper, Rangelcroft, Knussen, Lennings, Dixon, et al. 1986), a semi-structured interview, elicited parents' perceptions of their child's behaviour. The authors reported that both measures were shown to have high-internal reliability. The Malaise Inventory (Rutter, Tizard & Whitmore, 1970) was included to monitor stress levels, as it had been previously used to measure stress in carers of children with intellectual disability. Lastly, The Social Changes Questionnaire (Ball, 1995) was employed at follow up to collect information regarding changes to parents' social lives during intervention and whether these changes were regarded as positive or negative.

For the experimental group, significant improvement in self-concept was observed at follow-up and positive relationship changes were reported from the Social Changes Questionnaire. A total of 64% of the experimental group reported positive changes in their relationships with partners and new friendships while no changes were reported by the control group. The experimental group, however, did not report significantly different ratings of feelings about their children or judgements of their children's capabilities nor were there any significant changes in their perception of their children's behaviour. There was a significant increase in the ratings of judgements of children's capabilities by the control group. It was not possible to calculate the effect size from the data available.

The study also examined the influence of two factors on outcomes: single parenthood and previous attendance at special parenting service groups. Those parents at follow-up, who had previously attended groups, were found to have significantly higher judgements regarding their child's capabilities, implying that first time attendees may struggle to improve after a single, time-limited group intervention. They also rated their interactions with professionals and others more favourably. Single parents were found to be significantly more vulnerable to negative self-concept. The single parents within the experimental group rated their feeling about their children and interactions with others significantly less favourably and judgement of their child's capabilities significantly lower. They also rated the problem behaviours of their children significantly higher compared to parents with a partner, highlighting their increased vulnerability. There were no significant differences in reported stress between the experimental and control groups and there was no significant change in stress levels across time.

The intervention seemed to produce positive changes in parents' social relationships and, by follow-up, a significant improvement in parents' self-concept. Importantly, the study also investigated the influence of previous attendance and single parenthood on outcomes. The study used a range of validated outcome measures, although it was unclear to what extent they could be applied to people with an intellectual disability, particularly as some of the items were modified to ease comprehension. The measure of stress helped ensure that additional sources of stress did not confound the results, although there was a lack of detail regarding the psychometric properties of this measure. In terms of the intervention, there was limited information about what the control condition entailed and the concurrent teaching programme which both groups underwent. The study did not report the rate of drop out and it is unclear what numbers were included in the follow-up and as a result, the long-term effects

of this intervention seem unclear. Due to the design of the study, the authors highlighted that it was unclear whether participants improved as a result of the ‘feel good factor’ associated with group attendance or whether the taught component was the main factor for change. The small sample size and a short follow-up period limit the generalisation of the results.

McConnell et al. (2008) evaluated the pilot of the Australian Supported Learning Program (ASLP)-*Me and my community developed by* Australian Supported Parenting Consortium (2007). The programme, carried out across six sites, was designed to improve the social relationships and psychological well-being of mothers with intellectual disabilities. Participants were recruited by ASLP facilitators and were eligible if they had received a diagnosis of intellectual disability, had a history of special education, had received a disability support benefit or specialist services for adults with cognitive limitations and were identified by service providers as experiencing learning difficulties because of cognitive limitations. The authors did not provide information about the level of intellectual functioning of the participants. The programme was piloted by family support professionals who had been actively involved in the development of the ASLP. They all had experience of being group work facilitators with qualifications in psychology and social welfare. Their experience of working with people with intellectual disabilities varied from 0-20 years.

The number of mothers who participated per site varied from five to ten. The programme employed a problem-posing approach as participants engaged in a process of critical reflection on their own past and present experiences in the community. Three main approaches were employed to facilitate this process: the creation of a mural of the community referred to as a “discussion object”, a three step questioning strategy and a stepping stones activity to facilitate action planning. Participating mothers completed weekly home

challenges. They also received individual support to assist them with achieving their personal goals.

An ASLP Program Goal Achievement Scale was devised for the project to measure achievement of goals related to programme learning objectives and social relationships. This was administered to parents pre-group to ascertain how much they wanted to achieve each of the goals and post-group to evaluate their progress in achieving the goals. A personal goal attainment scale was also devised to promote social integration. Parents evaluated progress towards achieving each of their personal goals post-group. The study also employed a series of self-rating scales. The Tilden Interpersonal Inventory (IPRI)-Short form (Tilden, Nelson, & May, 1990) measured social relationships and has been shown to have high-internal reliability and good test re-test reliability. The psychological empowerment of mothers was measured using the Scales of Mastery and Constraints (Lachman & Weaver, 1998) which the authors reported had high internal reliability. The Depression Anxiety and Stress Scales (DASS-21) (Lovibond & Lovibond, 1995) which are also reported to have high internal reliability and acceptable test-retest reliability, were employed to measure psychological distress.

The largest observed effects were seen on measures of psychological distress ($d=0.50$) with the single largest effect being found for depression, which produced a medium effect size ($d=0.54$). The authors noted that while the effect sizes for interpersonal relationships (social support, $d=0.35$; perceived conflict, $d=0.08$) and psychological empowerment ($d=0.25$) were small, they were greater than those obtained by previous research on programmes with parents in the general population. The majority of mothers partially or fully achieved their personal goals they had set during the pre-group phase with 34% partially or fully achieving their priority one goal. Thirty-four percent of all the personal goals were

relevant to community involvement or participation. All mothers wanted to achieve each of the pre-specified program goals on the ASLP Programme Goal Achievement Scale. The most popular goals were “getting more enjoyment out of life” and “learning about my own strengths and things I am good at” with 80% wanting to achieve these goals “a lot”.

The results suggest that this group intervention may be beneficial in reducing psychological distress of mothers with an intellectual disability. The study had a number of strengths. The multi-site design ensured that participants were recruited from a wide geographical area and from both urban and rural settings. In addition, the inclusion criteria were relatively broad, although there was no formal measure of intellectual functioning, suggesting that the results could be generalisable to other groups and areas. In terms of the intervention, facilitator involvement in designing the programme was seen to promote consistency in implementation across the sites. There was, however, variability in the experience of facilitators, with some having had no experience of working with people with an intellectual disability which may have affected the delivery of the programme. In reference to the additional individual support offered to parents, it is unclear what this entailed and whether participants engaged in this. Furthermore, the design of a single treatment group meant the essential ingredient producing the effect was unclear. To help identify the factor of change, as the author acknowledged, future research would need to control for the taught component versus group attendance.

In terms of evaluation, a comprehensive number of scales were employed. However, issues related to their applicability to adults with an intellectual disability were not discussed, suggesting that the results should be interpreted with some caution. Furthermore, the outcome measures were administered by group facilitators which may have potentially biased the

results. In addition, neither the long term impact of the intervention nor the impact on the child were measured.

3.2 Conclusion: social relationship interventions

Only two studies, which met the review criteria, investigated group based interventions which were developed to improve the relationships of parents with intellectual disabilities. Both provided evidence of a positive impact on social relationships, although not in all of the outcome measures. McGaw et al. (2002) fulfilled few of the quality criteria outlined by SIGN (2008) whilst the single treatment group design employed by McConnell et al. (2008) meant it was not possible to carry out a formal quality assessment. If the SIGN RCT checklist had been employed then only 30% of the criteria would have applied to the study by McConnell et al. (2008) due to its less robust design. This implies that the conclusions drawn from this study carry less weight and should be interpreted with caution. The findings from the study by McGaw et al. (2002), according to the SIGN quality criteria, were given more weight as the authors adopted an experimental design higher in the hierarchy of study types. The study, however, achieved few of the quality criteria which suggests that it still has limitations and that the results should be interpreted with some caution.

3.3 Parenting skills teaching

A small study by Feldman et al. (1999) evaluated the teaching of basic childcare skills to parents with an intellectual disability through self-learning materials. The intervention was specifically tailored towards parents of children under the age of two years and centred on the use of an illustrated picture book with brief text, referred to as a manual. The majority of text was simplified. Skill checklists in the style of task analyses, which were piloted with

paediatric health professionals, were prepared along side the manual. The mother's performance on the checklist was recorded during home observations of the mother and child. A correct score was given if the mother performed the step as described in the task analysis without any instruction, prompting or assistance from the trainer. Parents, all except one of whom were under court-ordered supervision of a child protection agency because of reported high-risk for child neglect, were referred to the programme by community professionals. Most of the mothers had received a diagnosis of intellectual disability during childhood although updated assessments using the Wechsler Adult Intelligence Scale –Revised (Wechsler, 1981) were completed.

A baseline measure of a range of childcare skills was taken and those for which mothers scored less than 80% were targeted for intervention. This was based on previous research where mothers without an intellectual disability typically performed above this level. At the start of training, the mother was asked to read the manual aloud and feed back her understanding of the content to assess reading and comprehension ability. She was instructed to use the manual whenever she needed to perform the childcare skill illustrated. Acceptance of the manual was rated on a scale based on observations of whether the mother used it when asked to perform a task. No further prompting to use the materials was given. The outcome measure was the observed performance of actual skills recorded on these childcare checklists based on weekly observations. The follow-up period commenced after the mother reached the training criterion of 80% or higher after two consecutive assessment sessions. If there was no improvement after the seventh visit, full training was provided which was based on the work of Feldman, Case, Garrick, MacIntyre-Grande, Carwell and Sparks (1992) and included behavioural based strategies.

The reading ability of mothers and acceptance of the manual were significantly correlated with mean percentage correct scores during the manual stage. The intervention produced positive outcomes, defined as the percentage correct criterion for nine out of ten mothers and effects were shown to be sustained for up to three years. Six skills were successfully instructed. The mean number of sessions needed to reach the training criterion was 3.83 (range =2-8 sessions). For one mother, full training was required. Six mothers were asked a question to rate their satisfaction with the intervention.

The study had a number of strengths. The piloting of the checklists by relevant health professionals helped to ensure content validity of the measures used. The inclusion of a participant satisfaction scale, which produced mainly positive responses, also suggested the intervention had social validity. The authors also took account of potential confounding factors such as reading ability, comprehension and acceptance of the manual. The study also investigated the impact of the intervention in the longer term, although the period of follow up varied greatly between the mothers. While the study focused on a vulnerable group, the fact that the majority of mothers were under court-ordered supervision of a child protection agency, means that the extent to which the results can be generalised to other groups is unclear. In addition, as all the mothers were found to be functioning intellectually in the borderline range, despite having been diagnosed previously as having an intellectual disability, this raises questions about the applicability of the intervention to parents who have an intellectual disability.

Another small study evaluating the effectiveness of self-instructional materials for the learning of safety skills was carried out by Feldman and Case (1999). Parents had previously been independently diagnosed with an intellectual disability. There were, however, no details given about their level of functioning. Six of the 10 parents who participated were under

court-ordered supervision of a child protection agency because of concerns regarding child neglect. Inclusion criteria were: the parents were expecting or currently caring full -time for a child under two years old, they required training on a childcare skill for which self-instructional materials existed and had not been trained on the target skill by another worker. This intervention used illustrated manuals similar in design to those in the previous study but with the addition of audiotapes. Baseline skill level, skills to be targeted, percentage correct criterion and parental acceptance of the manual were all established in the same way as in the previous study. Reading and comprehension abilities were assessed, the former using the reading subtest of the Wide Range Achievement Test-Revised (Jastak & Wilkinson, 1984), the latter by asking the parent five standardised questions. The parent and trainer together listened to an audiotape where a woman's voice directed attention to the manuals and read the accompanying text. The parent was then advised to use the materials when carrying out the skill.

Parents were only advised to use the materials when first introduced to them. If there was no progress after approximately four visits, participants were given a prompt and reminded to use the manual. Prompts were repeated if there were no subsequent improvements. The study used a multiple baseline design across participants and the follow-up period occurred when the training criterion of 80% over three consecutive sessions was met. The time between observations gradually lengthened after the parent had successfully learned the skill. The mean number of sessions for those skills which met criterion was 5.5 (range 3-10).

The authors concluded that self-instruction was found to be effective with 9 out of 10 mothers, and the skills were maintained at a mean of four months. The 10 parents were taught 6 different childcare skills. One parent required full training after she failed to reach criterion

after ten visits and some participants still required prompts to use the manual during the follow-up period. No significant correlations were found between reading or motivation measures and percentage correct on checklists and number of sessions to criterion. A satisfaction questionnaire was completed by 5 of the parents and 90% of responses to the items were positive.

The strengths of this study were similar to those of the Feldman et al. (1999) study in terms of assessing the relationship of reading and comprehension abilities and acceptance of the manual with the outcome measure. In addition, the study had high inter-observer agreement in relation to the mothers' skills and efforts were made to check that the participants were not receiving any concurrent parenting skills from other professionals on the target skills.

The study limitations were also similar to those of the authors' earlier study in that the length of follow-up varied considerably between parents, the sample size was small and it was unclear to what extent the materials contributed to the learning of the skills, as the frequency of their use was not investigated. While these limitations means the generalisability of the findings in the study is limited, the results suggest that self-instructional materials may be effective for some parents.

A more recent study by Mildon et al. (2008) describes the pilot of an Australian based intensive home-based parenting programme for parents with intellectual disabilities of children aged 6 months to 6 years. The parents were recruited from a range of non-government and government agencies in an urban setting. The eligibility criterion was for participants to meet a functional definition of intellectual disability (see Tymchuk, Lakin & Luckasson, 2001). This meant parents were included if they had significantly sub-average general intellectual functioning concurrent with significant deficits in adaptive behaviour or

attended a special education school or had self-identified or been identified by the referring agency as having cognitive limitations resulting in difficulties with learning. The Kaufman Brief IT (Kaufman & Kaufman, 1990) was carried out with all but five parents.

The content of the program included three modules: childcare and home environment, parent-child interaction and Positive Behavioural Strategies (PBS). These were combined with strategies intended to facilitate the contextual fit of the intervention. Goals (2-5) were identified by each family with the support of the facilitator and the intervention was tailored to meet these by using the appropriate module content. A typical session focused on 2-3 specific programme goals and used behavioural based instructional strategies. The number of sessions received per family ranged from 10-26 over a six month period.

A range of standardised outcome measures were employed to evaluate the effectiveness of the programme. The Parenting Daily Hassles Scale (PDHS; Crnic & Booth, 1991) measured the frequency and intensity of hassles which occurred on a daily basis. The Parenting Sense of Competence scale (PSOC; Johnson & Mash 1989) measured the extent to which parents felt competent and confident in their role as parents with two subscales: satisfaction and efficacy. Both scales have been shown to have high-internal reliability (Crnic & Greenberg 1990; Johnston & Mash 1989). Parental perception of their children's behaviour was assessed using the Eyberg Child Behaviour Inventory (ECBI; Eyberg & Pincus, 1999). This measure shows high-internal reliability, good concurrent validity and is sensitive to intervention effects. The quality of the home environment was measured using infant/toddler and early childhood versions of the Home Observation for the Measurement of the Environment Inventory (HOME; Caldwell & Bradley 1984), which has high-internal reliability and adequate inter-rater reliability. A simplified version of a standardised "goodness of fit" assessment tool (Albin, Lucyshyn, Horner, & Flannery, 1996) evaluated

how successfully the programme matched each parents' goals, values and lifestyle. Finally, an interview was carried out with parents to measure consumer satisfaction.

Five families had goals which related primarily to the childcare and home environment module, eight families to parent-child interactions and six families to PBS. Significant reductions were found, post intervention, in the frequency of daily parenting hassles ($d=0.45$) and intensity of the child's behaviours ($d=0.55$) which both showed a medium effect size. There was a significant increase in mean scores for the early childhood version of the HOME ($d=0.72$). Results at three months follow-up were mixed, with positive changes being maintained in the PDHS, the efficacy subscale of PSOC and the overall score on the infant/toddler measure of the HOME. For the early childhood HOME measure, total scores decreased and mean scores on the satisfaction scale of the PSOC decreased slightly. The parent satisfaction scale demonstrated an overall high level of satisfaction. A goodness of fit questionnaire produced a high percentage of positive responses and the parents in general reported that the programme fitted well with their goals, values and family lifestyle.

This study had a number of strengths including: tailoring interventions to the needs and goals of each family; employing a range of validated assessments, an observational outcome measure and an indicator of participant satisfaction and a low drop-out rate. Although positive changes were observed, many failed to reach statistical significance. The authors offer possible explanations for this including insufficient strength, duration and focus of intervention. They also note that the sample size was small meaning that conclusions about the effectiveness of the interventions can't be arrived at until the results are replicated on a larger scale. Other potential limitations were that, although validated measures were used, they were simplified to facilitate understanding and it is unclear whether they have been previously used with adults with an intellectual disability. Related to this, it is unclear how

representative the sample was of parents with an intellectual disability given that it included mothers who were functioning intellectually in the average range. Finally, the lack of a control group creates the possibility that the results were due to factors other than the intervention. Overall, however, the results from the study are promising and warrant further investigation.

Llewellyn, et al. (2003) conducted a randomised controlled trial evaluating an Australian based Home Learning Programme (HLP) adapted from the UCLA parent-child Health and Wellness Project (Tymchuk, Groen & Dolyniuk, 2000). The programme was designed to equip parents of young children under five with the knowledge and skills necessary for managing home dangers, accidents and childhood illness. The sample was recruited from government and non-government agencies within an urban area. The study employed a functional definition of intellectual disability and excluded parents who had a diagnosed and unstable mental illness, a substance abuse disorder or who lived in a substantiated domestic violence situation. The following were administered at baseline: The Neale analysis (Neale, 1988) to provide a measure of reading ability; the Kaufman Brief IT (Kaufman & Kaufman, 1990) to measure IQ and the standardised SF36 Personal Interview (Ware, Snow, Kosinski & Gandek, 1993) as a subjective measure of health status.

The HLP was delivered by a trained parent educator in a one-to-one situation in the parents' home. The parent educator worked through a set of illustrated, plain English lesson booklets during their weekly visits and typically covered one topic per week. The project materials were checked by a small advisory group of parents with an intellectual disability who commented on the accessibility of materials. On their advice, additional graphics were added and simplified to increase accessibility and enhance interest for parents with low literacy skills. There were three alternative conditions: current community services, visits

only and lesson booklet only. The visits only involved a weekly informal visit to participants from graduate students to talk about their everyday experiences of raising their children. This did not involve any parent education. The lesson booklets only group received weekly lessons by mail utilising material used in the HLP. Parent educators kept in weekly contact with parents to check their progress on reading and implementing the information.

The study incorporated an array of health and safety outcome measures specifically devised for the HLP programme. The trained parent assessor who carried out the measures was blind to the condition to which each parent was allocated. Five of the outcome measures comprised knowledge and skill tasks relating to child health e.g. health comprehension. These showed acceptable internal reliability. Three measures related to home safety two of which were pictorial based tasks requiring the identification of home danger and precautions and one a home observation checklist. The authors reported that the three measures showed high-internal reliability.

At post-intervention, the parents who participated in the HLP showed a significant improvement in their ability to recognise home dangers and to identify precautions to effectively deal with these dangers in comparison to all other conditions. These parents also showed an increased use of health related words and body parts and in the number of safety precautions they implemented in their homes compared with lesson booklet condition. By contrast, the parents in the latter group and the HLP group showed a significant increase in knowledge about visiting the doctor and how to use medicines safely compared with other groups. Gains in the HLP group were maintained at three months post-intervention with the exception of the implementation of home precautions and the health comprehension measure. A few relationships were found between parent characteristics and parent learning (pre-post HLP) and maintenance (pre HLP-3month follow-up). Parent reading accuracy was

significantly correlated with health comprehension indicating that parents who read more accurately learned less on this outcome measure. There was a significant positive correlation between maintenance of knowledge and physical functioning and between parent IQ and maintenance of knowledge of life threatening emergencies. Parent literacy, reading comprehension and reading accuracy were negatively correlated with mean scores on the knowledge of life threatening emergencies and knowledge and skills associated with illness and symptom recognition.

The strengths of the study were the inclusion of control groups (although limited information was provided about what ‘current community services’ entailed). A comprehensive number of outcome measures were used, although no information about their applicability to people with intellectual disabilities was provided. The analyses of parental characteristics allowed the effectiveness of the interventions to be determined irrespective of the state of health, literacy skills or IQ. In addition, the learning materials were piloted by people with intellectual disabilities, ensuring content and social validity and the follow-up period allowed some measure of the maintenance of skills and knowledge over time. However, numbers were low at the three months follow-up, and the long-term effects of the intervention would benefit from further investigation. A further limitation was the inconsistent level of input across participants. The study suggests that while the other forms of intervention were effective, overall a more intensive behavioural based parenting programme was found to be more effective.

A more recent small unpublished thesis paper carried out an exploratory study of the curriculum-based CARE to Parent Program of parenting skills (Brisson, 2010). CARE is an acronym for Care, Attunement, Responsiveness and Empathy. The American programme was designed to strengthen and support the relationships of mothers with intellectual disabilities

and their children through improving mothers' attunement to their children as well as fostering greater resilience in the child. The mothers were recruited through several agencies and chosen to participate based on their motivation, location, children's ages, involvement with Department of Child and Family and their IQ. The participants were diagnosed with intellectual disability and each had a school age child who also participated. The study provided detailed characteristics of each mother and child. Modules were delivered through didactic teaching, completing worksheets and playing card and board games. The participants were allocated homework between sessions to help practice what they had learned. They completed an evaluation at the end of intervention.

The study employed the Parent-Child Interaction II (Holigrocki, Kaminski, & Frieswyk, 1999), an analogue behaviour assessment tool to evaluate the mother and child's relationship and level of functioning. The parents and children were videotaped going on an imaginary trip to the zoo. The videos were coded by two raters using the Global Assessment of Parental Attunement version 2.1 (Kaminski, Warren, Austin, Jooste, Casto, Holigrocki et al. 2006) to measure attunement and misattunement between child and parent. The results overall were equivocal. Contrary to the hypothesis, analysis showed a decrease in initiative attunement ($d=-0.73$). However, there was a decrease in initiative misattunement ($d=-0.69$) and increased physical attunement ($d=0.76$) supporting the hypothesis. The between subject analyses found two participants demonstrated an increase in parent-child attunement and a decrease in misattunement following the program whilst the remaining two mothers showed the opposite effect.

This study addressed an area that the author acknowledged seems to have been generally overlooked in parenting interventions. The participant evaluations indicated the intervention was generally viewed positively and suggested some mothers were generalising

the skills learned. The observational tools were clinically valid and had satisfactory inter-rater agreement despite not having been used with adults with an intellectual disability. The impact of the intervention on the child was not formally assessed and there was no control group or follow-up period. The study had a potentially biased sample through recruiting more willing and motivated participants. The sample size was very small and the author acknowledged that the limited aggregate data were not conclusive.

3.4 Conclusion: skills teaching interventions

This review indicates that there are limited evaluative studies of skill teaching interventions for parents with intellectual disabilities. Four of the studies were classified as a before-after study/interrupted time series which meant they could not be formally assessed (SIGN, 2008). This implies that, despite encouraging results and interventions which seemed to be effective for some parents, these studies carry less weight and there is a need for more robust research to enable firmer conclusions to be drawn. There was only one study which could be assessed according to SIGN (2008) quality criteria. This adopted a randomised controlled trial design and indicated that a behavioural based skills intervention can be more effective than less intensive forms of input such as lesson booklets and the provision of normal services (Llewellyn et al. 2003). The findings from this study were encouraging, however, only some of the quality criteria were satisfied (SIGN, 2008). All interventions adopted behavioural strategies recommended by Feldman (1994) and included homework activities to facilitate the generalisation of skills. None of the studies evaluated the homework component although Brisson (2010) found that two mothers in their study regarded it as helpful. The generalisation of skills was not investigated.

4. Overall conclusion

No firm conclusions can be drawn from the studies reviewed here. There were indicators that all of the parenting interventions reviewed were effective for some parents, although there were a number of factors which may have potentially biased the results. These included small sample sizes, lack of generalisability of data, the lack of or limited length of follow-up data, a lack of information about fathers with intellectual disability, lack of outcome data regarding the child and limited data on the intensity of interventions and concurrent interventions. There was a reliance on self-report measures in many studies which may be susceptible to biases. Adults with intellectual disabilities are especially prone to acquiescence which may have also impacted on the responses given (Finlay & Lyons, 2002).

The risk of bias was more systematically explored through the application of the SIGN quality assessment framework (SIGN, 2008). Five out of the seven studies included in the review, however, were of a design that could not be formally assessed using this framework. This implies that the majority of studies included in the review were too low in the hierarchy of study types and too susceptible to methodological biases to arrive at any firm conclusions regarding the evidence presented. The two remaining studies were found to be more robust and were given more weight in terms of the evidence provided. However, they need to be interpreted with some caution given the number of quality criteria they were found to satisfy. The use of the quality assessment framework further demonstrates that, overall, no firm conclusions can be drawn regarding the effectiveness of parenting interventions for adults with intellectual disabilities and that more robust research is required.

Several of the studies employed broad inclusion criteria which, in some instances, included participants who had IQ scores that fell within the low average or average range of

intelligence. The extent to which the findings are representative of parents with intellectual disabilities should, therefore, be interpreted with caution.

The review has highlighted the need for further larger scale, controlled studies in order to provide clearer evidence about which components are effective, for whom and for how long, in interventions for parents with an intellectual disability. There is also a need for further exploration of the extent to which additional factors such as parental stress and health status impact on outcome in order to maximise the potential of parents with an intellectual disability becoming “good enough” parents.

Research highlights are available in Appendix 5

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2. Aims of the research

As highlighted in the previous chapter, some of the research on parents with learning disabilities has focused on evaluating interventions designed to increase parental competence and help parents parent their child satisfactorily. Research has also focused on how parents with learning disabilities view the support they receive, both in the context of formal supports (e.g., service providers, professionals) and informal sources (e.g., family members, partners). Mayes *et al.* (2008) propose that how parents with learning disabilities perceive the support they receive and how comfortable they are in requesting this could potentially influence how parents with learning disabilities parent their children.

Llewellyn (1995) explored the views of parents with learning disabilities about their relationships and social support for parenting. They found that parents demonstrated a sequence of seeking help beginning with their partners, then family members and ending with professionals. Support from professionals was not consistently employed. There was a tendency for parents to feel professionals ignored any difficulty they had in understanding and learning new concepts or gave conflicting advice. Guinea (2001) carried out a study viewing the perceived and desired levels of support of eight parents with learning disabilities. Whilst family supports dominated, professionals were perceived as helpful by most parents in providing both emotional and practical support, with the majority of participants expressing a wish for more support. Llewellyn and McConnell (2002) carried out interviews with mothers about the type of support they received and from whom they received it. Service providers were seen as key sources of information and advice, however, parents generally disclosed feeling a lack of closeness to this group or feeling comfortable asking for or receiving support.

There is a small but evolving evidence base focusing exclusively on parents' experiences of formal support (Booth & Booth, 2005; Tarleton & Ward, 2007). Tarleton and Ward (2007) interviewed a cohort of thirty parents with learning disabilities to examine their experiences of positive support from professionals and service providers. Parents identified types of emotional and practical support which enhanced their ability to develop parenting such as feeling listened to, help with learning new skills and forming trusting relationships.

A more recent study by Starke (2010) explored the views and experiences of seven Swedish mothers with learning disabilities in their encounters with different health and social service professionals. The authors found three distinct themes emerged from their interviews. Firstly, a lack of comprehensibility was experienced by mothers during their interactions with support workers. This resulted from a lack of information and a perception of not being treated properly, for instance feeling blamed and judged. Several of the mothers, however, reported receiving support that benefited their parenting ability which was experienced as empowering. Thirdly, mothers perceived themselves as subjects needing support.

It remains unclear whether the needs of new mothers with learning disabilities are being successfully met during the postnatal period. Childbirth is a significant life event and one that marks a woman's permanent transition to motherhood. The postnatal care a new mother receives is important in facilitating this transition by providing a supportive environment for both her and her child to thrive (Demott *et al.*, 2006). It is, crucially, a time when parents first learn to nurture their child. Given that childcare is typically identified as an area of support by parents with learning disabilities (Kroese *et al.*, 2002; Starke, 2010; Tarleton & Ward 2007), it has been emphasised in recent guidelines that parents with learning disabilities be supported to access generic postnatal services (Department of Health & Department for Education and Skills, (DOH) 2007; Tarleton *et al.*, 2006). Services, however, may lack the

confidence and expertise to support parents with learning disabilities (Llewelyn & Bridgen, 1995; Tarleton *et al.*, 2006). Furthermore, previous research has revealed a discomfort in attending generic services such as pre-postnatal groups on the part of mothers as they feel they may appear different from the others (Martin, 2002; Tarleton *et al.*, 2006).

Postnatal services aim to promote the emotional and physical health of new mothers (Demott *et al.*, 2006). It has been identified that new mothers with learning disabilities may experience undiagnosed mental health problems during the postnatal period (Cotson *et al.*, 2001; O’Keefe & O’Hara 2008). O’Keefe and O’Hara (2008) have emphasised that mothers with learning disabilities, in general, experience more severe depressive symptoms. However, research employing the Edinburgh Postnatal Scale, routinely used to diagnose postnatal depression, suggests that this may not be a reliable instrument when applied to this population (Gaskin & James, 2006).

Despite this pivotal time of re-adjustment for mothers with learning disabilities, there has been, as far as the researcher is aware, no research exploring their experiences of service provision during the postnatal period.

To fill this gap in research and help inform service provision, this study aims to explore the question: How do mothers with a learning disability experience postnatal care?

3. Methodology

The aim of this chapter is to describe the methodology of the research. It will cover the design of the study and will outline the procedures through which the data was collated and analysed.

An overview of the theoretical background will be provided and the rationale for the approach selected. This chapter will also cover important ethical issues and the characteristics of the participant sample.

3.1 Study design

To address the research question which explores the postnatal care experiences of mothers with learning disabilities, it was identified that a qualitative design would be most appropriate. Qualitative research aims to make sense of and reflect the experiences or behaviours of people as they meet, become involved in and live through situations (Elliot *et al.*, 1999). Quantitative research, in comparison, focuses on testing a hypothesis or causal relationship (Elliot *et al.*, 1999). The following qualitative approaches were considered: grounded theory, phenomenology and discourse analysis. Grounded theory aims to develop an explanatory theory of basic social processes and there are now different versions of the method in use (Willig, 2001). It relies on theoretical sampling, thereby recruiting participants who have had different experiences of the phenomenon under study (Starks & Trinidad, 2007). The researcher continues to add to the sample until the research reaches theoretical saturation. Phenomenology aims to establish a deeper understanding of lived experience through close examination of individual experiences (Starks & Trinidad, 2007). Such an approach tries to capture the meaning and common features of an experience or event. Discourse analysis, on the other hand, examines how knowledge, meaning, identities and

social goods interaction are constructed through language and language use (Starks & Trinidad, 2007). It is through the shared, mutually agreed on use of language that meaning is created rather than the language and words themselves.

The purpose of the study was to gain an understanding of lived experiences of people with learning disabilities. Discourse analysis, although it examines the way in which meanings are constructed, was deemed an unsuitable approach due to the potentially limited language abilities of the participants. Grounded theory was disregarded due to its aim of deriving an explanatory theory and attempting to identify and explicate social processes which account for a phenomena (Willig, 2001). A phenomenological methodology seemed the most appropriate approach, as it explores the understanding of the quality and texture of an individual participant's lived experiences. Although it has similar analytical techniques to grounded theory, phenomenology is interested in the nature or essence of phenomena. The chosen phenomenological approach was Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA offers an insight into an individual participant's psychological world and is, therefore, regarded specifically as a psychological research method (Willig, 2001).

IPA involves a "double hermeneutic" (Smith & Osborn, 2008). The researcher is making sense of the participant who is making sense of their experience. This acknowledges that the researcher has access to the participant's experiences through what the participant reports and through the researcher's own interpretation and interaction with the participant. An additional feature of IPA combines a hermeneutics of empathy with a hermeneutics of questioning (Smith *et al.*, 2009). This means that, in conjunction with understanding the participant's experience, the researcher, also attempts to understand things from an alternative perspective, thereby asking probing questions and adopting a more critical stance.

The collection of data for IPA requires a method which will help to elicit from the participant in-depth stories, thoughts and feelings. Semi-structured, one to one interviews were chosen as they have tended to be the preferred means for collecting such data (Reid *et al.*, 2005). The participant group was recruited using purposive sampling as the research was looking to explore the understanding of a particular life experience. A sample size of between four and ten was recruited as recommended for a professional doctorate using IPA (Smith *et al.*, 2009).

3.2 Researcher's perspective

I am currently a trainee psychologist in my final year of study. Before I started the training I was a support worker/assistant psychologist working with adults with learning disabilities. This experience gave me a fascinating and useful insight into how people with learning disabilities of varying abilities, ages and socio-economic backgrounds experience life. It enlightened me to the important role services play in the lives of this population in maximising their quality of life and the challenges this inevitably entails.

For the past two years on the Programme, I have been on placement in a community adult learning disability service. This has included working with parents with a learning disability conducting cognitive assessments and therapeutic work. This led to the experience of working with mothers who found the demands of parenthood, coupled with managing their emotional problems, a challenge. The proximity of informal supports seemed key to the mothers fulfilling their role but the quality of the relationships also seemed important. I also worked with parents who experienced the removal of their children which appeared to have a far reaching impact on their lives. It could, at times, restrict their ability to access community activities, as seeing other parents with their children out in the community was a painful and

constant reminder of their own circumstances and separation from their child. It also elicited feelings of failure as they felt judged negatively by people in the community.

For some parents, there was a longing to have another chance to do things differently and had they realised the implications at the time of not working more collaboratively with professionals, they would have acted differently. What emerged strongly from my work with most parents, was the time and energy invested in regaining their child and having them back home where they perceived they belonged. This appeared, for many, to be a long drawn-out and agonising process.

Given my experience, I was interested in further developing my learning and research skills in this area and thus I have approached this study from the perspective of a professional working within the field of adult learning disabilities. I anticipated that the role of being a mother would shape the existence and purpose of many of the women I would interview. For those mothers who no longer had their children, I expected that there might be strong feelings of resentment towards certain professionals and powerful feelings regarding their current separation from their child. I was aware that, by carrying out research in this area, I would inevitably have to cope with highly emotive material and that remaining non-judgemental would be paramount.

3.3 IPA and learning disability

IPA is increasingly being employed in clinical and health settings (Smith *et al.*, 2009). The advantage of an approach such as IPA is that it enables adults with learning disabilities, a population who may have been excluded in the past, to have their voices heard (Nind, 2008). An increasing number of studies with adults with learning disabilities, including parents, have adopted an IPA methodology (e.g. Baum & Burns, 2007; Mayes *et al.*, 2008).

Although conducting qualitative research with adults with learning disabilities may present challenges, it is still regarded as achievable. Two studies have explored the application of qualitative methods to adults with learning disabilities and a number of recommendations have arisen from this work (Booth & Booth, 1994, 1996). Booth and Booth (1994) advised that the researcher view rapport as a two way process with information gathering and giving. In accordance with this recommendation, the researcher explained to participants when providing information about the study, that she would be happy to answer any appropriate personal questions relevant to the research.

Booth and Booth (1996) also address the challenge of using narrative methods with people with learning disabilities including inarticulateness and unresponsiveness. They advised adopting a “self- developing” technique i.e. adapting communication as required as the interview progresses, in response to difficulties that arise. This might include adopting simpler language, avoiding abstract questions and keeping to one point at a time. They also note that the researcher may have to ask more questions and probe more fully to elicit information. This may include considering the form of the questions and the type of language employed. They recommend that a level of communication is established that facilitates rapport without causing a feeling of inadequacy and that it might be possible for the researcher to make suggestions to help determine in what direction the participant’s story unravels.

The researcher referred to the recommendations from these studies when carrying out the interviews.

3.4 Ethical Considerations

3.4.1 Ethical Approval

Ethical approval was granted by the University of Edinburgh Programme Team. Approval was also granted by the South East Scotland NHS Ethics committee (Appendix 6). Lastly, approval for the study was also sought and given from the Research and Development (R & D) department in the area where the participants were to be recruited from (Appendix7).

3.4.2 Ethical Issues

A high number of parents with learning disabilities are unsuccessful at being “good enough” parents and have their child or children removed by child protection agencies, mainly due to neglect or emotional abuse (Cleaver & Nicholson, 2005). It was important, therefore, that participants were informed of the limits of confidentiality. It was made clear to each participant that, if any risk of harm to their child or children was disclosed, child protection proceedings would be followed. It was also explained that if concerns were raised regarding the mother’s own welfare, the relevant person within the Community Learning Disability Team (CLDT) would be contacted. There was the possibility that participants, particularly those who had experienced the removal of their child by welfare authorities, would become distressed during the interview. If this did occur, the researcher would respond appropriately to the clients’ needs drawing on her clinical skills. This might include checking with the participant that they wished to continue with the interview.

Adults with learning disabilities may be susceptible to acquiescence (Finlay & Lyons, 2002), therefore, participants were asked questions to assess their understanding of the study and the potential implications of participating. If the participant wanted to talk about further issues raised during the interview, they were advised to contact someone in their pre-existing

network, including someone in the CLDT. The participants were encouraged to contact the researcher if they had any concerns relating to the research. They were also provided with the name of someone to contact should they wish to talk to someone else about the research.

The CLDT Personal Safety and Lone Working policy was adhered to when carrying out the research. This included updating the researcher's electronic diary with details of the interviews. Following the interview, the entry was deleted from the researcher's diary to maintain participant confidentiality. For interviews which occurred at the end of the day, the researcher's supervisor was informed of her whereabouts and a text was sent following the conclusion of a visit.

3.4.3 Informed Consent

As mentioned above, the participants may be vulnerable to acquiescence (Finlay & Lyons, 2002) and given the cognitive difficulties associated with having a learning disability, it was important to ensure that participants possessed the capacity to consent to the study.

A screening interview was carried out with the participants before conducting any interviews. During this, the participants were provided with a description of the study by way of the Participant Information Sheet (see Appendix 8). The Participant Information Sheet ensured that those taking part were made aware of potential ethical issues. It was presented in an accessible format and was read to the participants at an appropriate pace to facilitate their understanding.

The researcher asked questions to assess the capacity of participants to consent to the study including their understanding of what taking part in the study would involve, the potential benefits and burdens in taking part and checking they understood that there was an alternative to taking part.

At the time consent was obtained, participants were initially assigned a code that was used to identify their interview. During the analysis, participants were given a pseudonym to protect anonymity and ensure confidentiality.

3.5 Participant Recruitment

Participants were recruited through a Community Learning Disability Team (CLDT) comprising NHS and Social Care staff. This included Psychiatry, Nursing, Social Work and Allied Health Professionals (AHP) such as Speech and Language Therapists, Occupational Therapists and Dieticians. Potential participants were identified by members of the team who, through their clinical practice, had encountered participants who met with the inclusion criteria. The study included mothers with a learning disability (aged over 16 years) who had current or past input from the CLDT. The study excluded mothers who were unable to give consent due to physical or mental health problems and those who were currently going through child protection procedures who may have been significantly distressed by participating. A member of the CLDT, who was familiar with the potential participant, made the initial approach to see whether the mother was interested in participating. If so, her consent was sought to have her contact details (home address and telephone number) passed on to the researcher. The researcher contacted the potential participant to arrange a time to carry out the initial screening interview. After completing the screening interview, participants were given 24 hours to decide whether they wanted to take part in the study. They were then telephoned so their decision could be given. If the participant consented to taking part, a time was arranged to either meet at a local health centre or the participant's home to carry out the interview. At the beginning of the interview session, the researcher checked with the participant that they understood what the study was about, the implications

of taking part and that they still wanted to be involved. Written consent was gained from the participant (Appendix 9) before starting the interview.

3.6 Data collection

Initially, current literature on the postnatal care experiences of parents in the general population and adults with learning disabilities was consulted. The literature on IPA was also referred to. This contributed to the development of a semi-structured interview schedule (Appendix 10). After consultation with the researcher's supervisor, modifications were made to the wording of selected questions. Before commencing the interview, the researcher again checked with the participant that she understood what the interview was about, the implications of taking part and that she still consented to it. The participant was reminded that the interview was about hearing her story and that there were no right or wrong responses to the questions asked. After it was initially established when the participant's child was born, the researcher then asked "tell me about having your baby". The researcher then employed prompts to explore a participant's responses and referred to the interview schedule. The interviews lasted between 57-69 minutes. Four of the interviews were conducted in the participants' homes and two in the health centre. There were some brief interruptions during three of the interviews at home. In one instance, the husband twice entered the room and interrupted the conversation. On the other two occasions, the interview was briefly interrupted by the telephone. One participant had a friend with her during the interview and another had her husband. The interviews ended when judged to have come to a natural conclusion. The researcher checked to see if there was anything the participant wished to add. She then summarised the main points from the interview and enquired if there was anything the participant wished to ask.

Following the completion of an interview, the researcher logged her experience of the interview from her perspective and her initial thoughts on the participant's experience and personal story.

3.7 Participant characteristics

Screening interviews were carried out with thirteen participants, seven of whom met the exclusion criteria or were unwilling to take part. Thus a remaining six participants indicated an interest and gave informed consent to take part. The six mothers were from a small rural community and the results will be reported as a group to help maintain confidentiality.

Participants were aged between 20 and 55 years. Two of the participants were single and three lived with a partner. One other participant was married and currently lived with her husband. All of the mothers had experienced one or more of their children being removed by child protection agencies. For two of the participants, this was the only child they had. The other participants had between 2 and 8 children. The ages of the participants' youngest child ranged from 10 weeks to 15 years.

3.8 Data analysis

The analysis of the data adhered to the process outlined by Smith *et al.* (2009). The process began with the researcher becoming immersed in some of the original data. This started with listening to the audio recording whilst transcribing followed by reading and re-reading the data. The researcher whilst doing this, tried to imagine the voice of the respective participant. This elicited significant recollections from the interview experience and these were noted in a reflective log. See below for illustrations:

Seems to feel she was left unsupported but repeatedly makes reference to resisting and pushing away professional support-because she feels undermined? Didn't see them as support? (Donna, 23.05.10)

More aware of how she seemed to direct the conversation. Very much tended to avoid lingering too long on negative aspects and would start referring back to the attention they received and the joy of the family around her and other positives-perhaps too painful to dwell on? (Jacinta, 16.05.10)

Such reflections were then set aside to help focus on the analysis and content of the interview.

The transcript was formatted with wide margins so that notes could be inserted on either side and the lines were numbered. Merging with the re-reading, was the process of making exploratory notes or comments. Through note taking, the descriptive content of the transcript was analysed, as well as the language used and initial interpretations. The notes were recorded on the left hand margin of the transcript. This exploratory note-taking process led to the development of emergent themes which were recorded on the right hand margin. At this point, the researcher shifted her focus to the exploratory notes rather than the transcript itself. The emergent themes, recorded on the right hand margin, were intended to reflect not only the participant's experience but also the researcher's interpretation. The emergent themes were seen to capture and reflect an understanding of the participant's experience. An example of this stage of the analysis is available in Appendix 11.

Once all the emergent themes had been produced, they were listed with page and line numbers of the verbatim extract they captured. The possible connections between listed themes were explored in order to generate clusters of themes. Each cluster was given a title

which represented a super-ordinate theme. Some themes were disregarded, as they were not sufficiently represented in the data or failed to fit with the emerging clusters. The development of clusters included putting like with like, a process Smith *et al.* (2009) refer to as abstraction. The process of subsumption (Smith *et al.*, 2009) was also employed which is when an emergent theme acquires a super-ordinate status. The researcher frequently referred back to themes to check that the groupings appropriately captured what the participant had communicated. This process was repeated for each interview. The researcher attempted to set aside the previous analysis while working on the next to facilitate the emergence of new themes. A table of super-ordinate themes along with the relevant sub-themes was produced for each participant (see Appendix 13). The page-line numbers for themes, in addition to extracts from the transcript, were included alongside each theme.

After the analysis of individual interviews, connections across cases were explored and super-ordinate themes for all the interviews were identified. This involved laying out the tables of super-ordinate and sub-themes for each participant and looking across them. The re-configuring, re-labelling of some themes occurred. The frequency with which themes occurred was considered and the relevance in answering the research question. The processes of subsumption and abstraction also occurred at this stage. A master table of themes for the group was produced showing the relevance of themes to each individual participant (see Appendix 12).

3.9 Ensuring quality

Qualitative research involves the interpretation of data. This is a process that the researcher actively engages in and this means qualitative research acknowledges a subjective element in the process (Willig, 2001). This means that the criteria employed to assess the quality of research such as validity, generalisability and representativeness, in their typical form, are irrelevant to qualitative research. Over recent years guidelines, specifically for assessing the quality of qualitative research, have been developed by several authors and were consulted in the present study (Elliot *et al.*, 1999; Yardley, 2000). The researcher had regular contact with her academic supervisor and this included reviewing the coding system, thereby conducting credibility checks as recommended by Elliot *et al.* (1999). This was conducted during the analysis of individual interviews and across cases. It is also recommended that the results are fed back to participants themselves and they are given an opportunity to remark on the results (Elliot *et al.*, 1999). Due to time constraints, however, this was not possible to complete during the analysis process and the results could not be validated in this manner.

It is important in qualitative research that the researcher openly reflects on his/her own assumptions, intentions and actions and how these may have affected his/her interpretation and understanding of the data (Elliot *et al.*, 1999; Yardley, 2000). This type of disclosure is commonly referred to as 'reflexivity' (Finlay & Gough, 2003). The researcher was given an opportunity to discuss with her supervisor factors relating to reflexivity and employed a reflective log throughout the process.

3.10 Reflexivity

Reflexivity is a process which:

“facilitates a critical attitude towards locating the impact of research(er) context and subjectivity on project design, data collection, data analysis and presentation of findings” (p22, Finlay & Gough, 2003).

As such, reflexivity is seen to enrich the quality of qualitative research through increasing the transparency and coherence of the research (Yardley, 2000). Wilkinson (1988) identifies three independent forms of reflexivity which are interrelated: personal, functional and disciplinary. Personal reflexivity relates to the researcher’s own motivations, interests and attitudes and reflects on how these may have influenced the research process. Functional reflexivity on the other hand, focuses on the researcher’s role and his/her interaction with the participant during the research process. Lastly, disciplinary reflexivity involves adopting a more critical stance through viewing the theory and method of the research in a broader context and considering its potential contribution to a particular literature. It is recommended that reflexivity is practised on these different levels when carrying out qualitative research (Finlay & Gough, 2003)

The issue of reflexivity will be re-visited in the discussion chapter.

3.11 Dissemination

All the participants expressed an interest in being informed of the results in person. Although this was not completed before completion of the thesis due to time constraints, it was anticipated that an accessible format of the results would be given to the participants. This would include an analysis of participants’ own results and an integrated analysis of all the interviews.

It was also anticipated that a copy of a research report would be provided to members of the CLDT.

4. Results

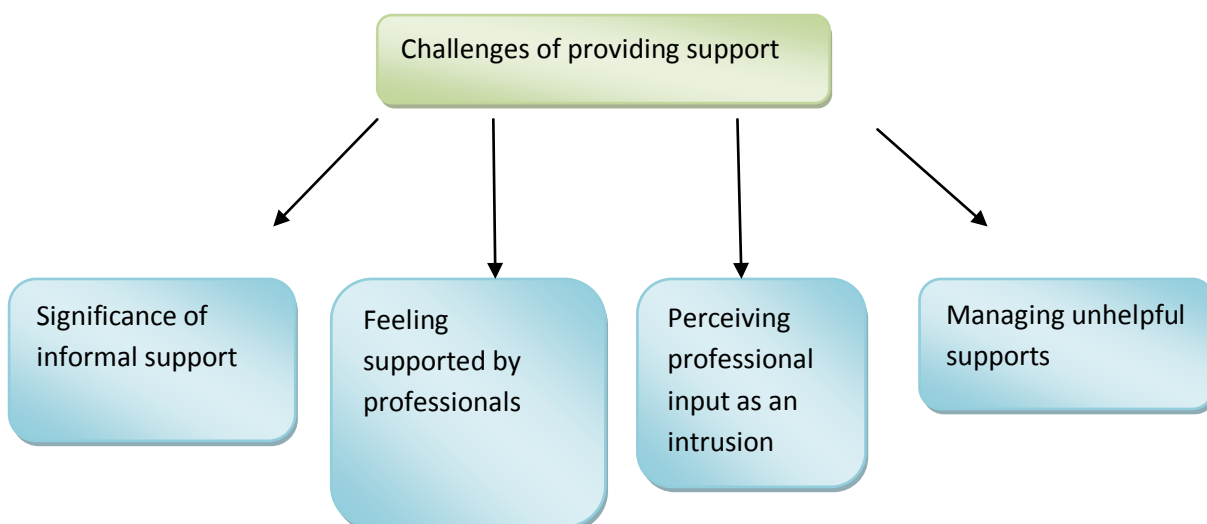
The aim of this chapter is to present the key findings from the analysis in the context of the original aim of the research which was to explore how mothers with intellectual disabilities experience postnatal care. The analysis produced four super-ordinate themes: ‘challenges of providing support’, ‘how support was delivered’, ‘learning how to cope’ and ‘challenges to building trust’.

The first super-ordinate theme identified from participants’ narratives, ‘challenges of providing support’, suggests that formal postnatal care was seen as secondary to that received from informal supports although it was valued by participants when delivered according to the standard pathway of care. The following super-ordinate theme ‘how support was delivered’ encapsulates the importance of how interactions with professionals were perceived by participants. The third super-ordinate theme, ‘learning to cope’, illustrates that, despite being in receipt of postnatal care, there were aspects of becoming a new mother which participants found difficult to cope with and the impact this had on professional involvement. The fourth theme, ‘challenges to building trust,’ encapsulates the importance of trust and the influence of past experiences on the forging of the relationship between professional and participants.

All four super-ordinate themes will be examined individually with excerpts from the transcript to illustrate. Pseudonyms have been used for the names of participants, their respective partners, children and relatives to ensure confidentiality.

4.1 Challenges of providing support

Whilst the aim of the study was to explore participants' experiences of formal postnatal care, family members appeared to emerge as a key form of support during this period. All of the participants spontaneously referred to family or significant others as providers of support in their lives even when the support given was, at times, unsatisfactory. It seemed, from the participants' narratives, that input from professionals was valued. However, it was generally considered secondary to that received from family members and its value seemed limited to the care typically received from the mid-wife and health visitor post-birth. There was the suggestion that providing more intensive input could present challenges.



4.1.1 Significance of informal support

The support provided by loved ones, particularly by mothers of participants or their partners, was clearly significant during the postnatal period. Different types of support were experienced, however, the value of these varied. Instrumental support such as help with material goods and emotional support were regarded as beneficial but most participants focused on the value of practical support.

If he's there we have turns about feeding. Em, if I'm eating my breakfast John (partner) will take over, like with everything like I'm having my lunch and even at tea time, he'll do stuff as well like he'll put the dinner on and I'll see to Fraser and things like that. It's much easier with John being there. (p7, 304, Fiona)

She (her mother) came and helped us and dressed him, looked after him and like. (p10, 468, Betty)

The value of sharing practical tasks with her partner, including housework and childcare, seemed to feature strongly throughout Fiona's narrative suggesting this was something she needed assistance with. Betty more explicitly highlighted her need for support. It is clear that she felt that she benefited from her mother's experience and knowledge of how to perform childcare tasks. Her mother seemed readily available to her more so it seemed than her partner.

M: Well she had all the knowledge

T: Yeah

M: about what to do and all that. I done it myself. I done it a lot myself you know but she was good, she was great that way. (p10, 473, Betty)

Jacinta seemed to associate the support with childcare from her partner more with a sense of pride in her partner's willingness to engage in such tasks and fulfil his fatherly role rather than the benefits of sharing the demands of tasks.

Then I fell asleep about 9 o' clock and they says "Jacinta" , and I says "what?" , " Harry's here" and then I woke up and Harry was giving his daughter a feed," weren't you Harry? When I woke up at 10 in the morning?" So he changed her nappy and fed her. (p7, 336, Jacinta)

Donna, in her narrative, referred to episodes when she experienced fatigue and pain during the postnatal period. She emphasised the usefulness of the help she received with practical tasks such as childcare whilst coping with these physical effects.

..cause every time I needed a sleep or something, my mum used to take over, like Tom used to help my mum and that as well, like he used to feed the bairn as well, at that point, like, when I was sleeping and stuff even then I used to ask my brother "will you watch the bairn if I go to sleep for an hour?" and he says "aye no problem". (p15, 716, Donna)

A less recurrent type of support which applied to only two of the participants was the role that family members played in providing instrumental support. One participant, affected by monetary constraints, reflected on the financial support she received from family. Fiona, in contrast, appreciated the supply of clothes.

She (her sister) helps me out quite a lot with clothes for Fraser. She helps me out quite a lot with them. (p14, 702, Fiona)

There was an indication from participants that they relied on family members for emotional support. This seemed to feature most prominently in reference to participants' time in hospital where the presence of such significant people appeared most meaningful. This may have been due to the foreign hospital environment or the need for support during the initial stages of transition to motherhood.

It was nice to have two close people (mother & partner) there that mean so much to me there and to support me so that was really nice. (p5, 230, Ruth)

But at the hospital he was great. He was holding my hand and stuff like that. (p8, 391, Donna)

For two of the participants, emotional support was actively sought emphasising the dependency on family and significant others to provide this.

I was panicking obviously being a new mum and that and cause my ex could nae stay there at the time we were going oot. I had to get my mum to come back cause I didn't want to stay on my own. (p2, 96, Donna)

Participants seemed to rely heavily on family, predominantly mothers and partners, to provide support during the postnatal period. This was provided in various ways, but most prominently in practical childcare tasks which seemed to reflect specific areas of difficulty for the participants.

4.1.2 Feeling supported by professionals

Despite a strong emphasis on the support from family and loved ones, the value of professional input emerged in the narratives of all participants. In fact, many participants highlighted the importance of advice from professionals during their stay in hospital and the days following their return home.

Cause if you ever asked a question, they would tell you what to do and show you what to do but that was it. They wouldnae say you're doing wrong or that. (p8, 347, Jean)

The significance of being shown what to do seemed prevalent in many of the participants' accounts suggesting it was important in facilitating the learning of childcare tasks.

One of the midwives, one of the nurses, she gave me a hand and showed me what to do, like bath her. (p5, 245, Jacinta)

Cause it was my first kid you know, you want to learn and what you learnt was by watching you know, seeing what she did. (p8, 360, Betty)

Well before I had Lucy she would show us the birthing pool and things like that around the hospital, and talk to us about when it came to the weaning and that as well and just things like that. She was brilliant. (p12, 586, Fiona)

Fiona, in this excerpt, refers to an antenatal group she had attended run by her midwife. It seemed that she had valued the content of the group. Another participant spoke about attending a young mothers' group during the postnatal period and appreciating the opportunity to gain professional advice and extend her knowledge of practical childcare.

So we talk about weaning, what's good for them what's bad for them and things like that. We do some cooking and things like that, general discussion if we've got any worries about the baby, cause obviously there's a midwife there and you can ask questions and things like that. (p10, 466, Ruth)

Attending this group also appeared to provide Ruth with additional benefits. She appreciated having the opportunity to meet and socialise with other local mothers and subsequently felt that her confidence had grown. She appeared to have been apprehensive about attending this group, but the fact it was something that she had agreed to do before her infant's birth, gave her the impetus to do so. It seemed, from what she communicated, that the small size of the group had also facilitated her engagement.

Em I'm not as shy now, I can em, like if I don't know someone, I've got more confidence to actually speak to them rather than shy away from that person and try and engage wi' them. Whereas before, if I didnae ken someone, I wouldnae talk to them and I would sit in the corner and things and I'm getting much better, getting much better to socialise as well. (p9, 405, Ruth)

There was the sense that the advice from professionals was appreciated by Donna but more so when she could see that it was important. This implies there were times when she perceived the support provided by professionals as less important or its value was less clear or easily understood.

It was different with Mary cause she was cold. You had to have the water a certain temperature for the bairn for a couple of months or something and I dinnae mind them coming in and daein that cause that was important. (p11, 523, Donna)

This task may have been considered to be of particular importance as it was something which both Donna and her partner had found difficult to perform.

Half the participants conveyed the sense of feeling they had someone they could talk to and from whom they could gain some form of emotional support. This tended to be the midwife who was most involved in the children's care.

If you were upset like, Emma (midwife) was there to talk to. (p12, 581, Fiona)

It was only one midwife but she was doing most of the care for me and baby so it was really nice and she was the one who set me aside in another room and let me speak and cry and she was there. So she was really good and if I had a problem then I would speak to her also, it was good I had a nice relationship with her. (p7, 308, Ruth)

Betty also seemed to feel that her midwife made herself available, but it also appeared significant to her that the midwife was empathetic to her situation of becoming a new mother.

...cause she knew what I was going through cause it was my first kid you know. (p8, 361 Betty)

Although it seemed greater emphasis was placed on the practical support from professionals, a number of participants still appeared to value feeling cared for emotionally and having someone who was accessible and empathetic to their situation. This tended to be the mid-wife or nurse, someone who had regular contact with the mother and who was, therefore, more familiar.

4.1.3 Perceiving professional input as an intrusion

Despite seeming to value the support from professionals, four of the participants had experienced more intensive input after the birth of at least one of their infants. From their narratives it seemed that when support was more intensive and exceeded the standard pathway of care, it was viewed less favourably and the presence of professionals seemed almost relentless.

They were in and out like yoyo's (p8, 380, Fiona)

T: And was there staff there?

Yeah, every five minutes, they were always interfering, I says "get out", I know what I'm doing (p10, 488, Jacinta)

The continued presence of professionals seemed to have a negative impact on the life of participants as implicated in the excerpt above by Jacinta. It seemed as if the presence or

continued input of professionals lowered mothers' perceptions of their own capabilities. As a result, Jacinta ended up trying to resist receiving the support and a similar suggestion of the negative affect was demonstrated by other participants.

..It wouldnae have bothered me to have them there as long as they didnae crowd me too much, cos that's what they done.....there in my face all the time, and I couldnae cope with it (p8, 374, Fiona)

So basically that's why I came back here early (to her own house) to get away from them all (p12, 559, Donna)

For Jacinta, the continued presence of professionals appeared particularly unwelcome and was viewed as an invasion of her privacy suggesting she may not have fully understood the purpose or reasons for the professionals becoming involved.

..they wanted to know our private affairs and what we do with Mary and that and I dinnae like that (p14, 672, Jacinta)

There was also the added sense that the presence of professionals interfered with her image of the perfect family set-up.

For Ruth, it seemed that the continued involvement of social work was identified as particularly unhelpful. The reason underlying this seemed to be the failure to provide something tangible. Their visits were regarded more as an unwelcome intrusion which

induced a sense of disempowerment in her role rather than seeming to make her feel supported.

They don't really do anything, I don't ken if it's support to be honest wi you cos all they do is come in saying "Hi-ya, how's you? How is the baby? How are things between yourselves?" things like that I don't see that as a support, cost that's just normal chitchat (pause) cos like for me, if we were stuck with money or something and they could like give us a loan of money something, that's supporting us, not actually just saying "hi-ya how's you?" I don't think that's support at all (Ruth, p16, 758)

More intensive input seemed to elicit negative responses from participants and, by some, it was met with resistance.

4.1.4. Managing unhelpful supports

It appeared from the narratives of several participants that there was the continued presence of unhelpful informal supports during the postnatal period. Jean seemed to feel that she suffered as a result of the absence of practical support. Although she had a partner at the time, he did not seem to offer any support with caring for their new infant and Jean clearly felt frustrated by this.

...cause he (her partner) wasnae helping us ken he was just sitting watching telly and everything. He wouldnae feed the bairn or change the bairn, he would just sit and watch sport all the time. (p2, 63, Jean)

From Jean's account, she did not seem to feel able to be assertive with her partner and avoided any confrontation.

The quality of support from family members for two of the participants seemed questionable at times. Donna felt that, although she had a partner and family who were willing to help with the child-care, the quality of the support varied and was, at times, unhelpful.

...cause I wouldnae let (partner) bath her cause when (partner) bathed her one time, he made the water far too hot, and when he pulled the bairn out of the bath she was all red and he burnt her. So I had to buy some cream for the burns and stuff and then I still, for quite a bit I wouldnae let him do nought with the bairn cause of that. (p10, 494, Donna)

Although Donna stated that she would not accept any further help from her partner, there was an indication from content revealed later in the interview that he remained actively involved in the care of their new infant. The fact Donna remained reliant on her partner's input, despite its quality, may be seen as an indication of how much she needed the support to fulfil her mothering role. This need for support similarly extended to her brother on whom she continued to rely on even when she was unable to supervise him.

... he took my bairn to the pub, and I wasnae happy wi' it cause she was only a couple of weeks old and em so, what I done was I wouldnae let him take her anywhere unless I was wi him. (p6, 252 Donna)

There was a sense from Donna's interview that she seemed to have difficulty asserting herself with her brother who seemed to almost intimidate her at times. This could potentially have contributed to the reason for his continued inclusion in the care of her infant. For Jacinta, the difficulties which her partner seemed to have with child-care on occasions were disguised through the use of humour.

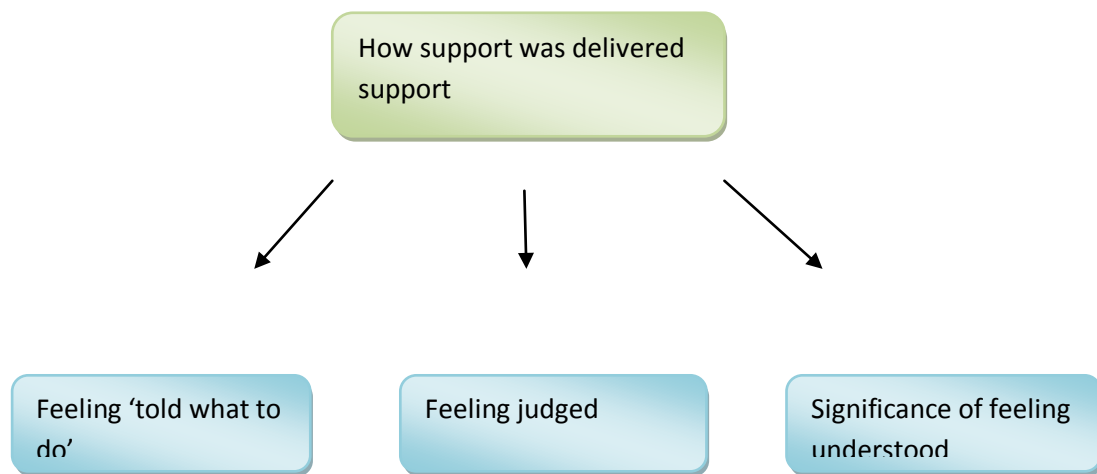
.....one time I bathed Mary when Harry was in and I was laughing you put on a nappy and put it on the wrong way round (laughing), it was funny. (p6, 258, Jacinta)

It seemed that she was reticent to convey any sense that they were struggling with their parenting role. Instead, she was focused on communicating the idea of being part of a perfect family unit.

Some participants seemed to rely heavily on informal supports even when they recognised this support was sometimes questionable.

4. 2. How support was delivered

It emerged from all participants' accounts that how they perceived support to be delivered by professionals was a significant issue. Many of the participants identified positive and negative practices on the part of professionals during the postnatal period which seemed to impact on their experiences of care.



4.2.1 Feeling 'told what to do'

Participants did not view favourably professionals who seemed to give advice in a way that felt as though they were being “told what to do”. In other words, advice delivered in what was seen to be a more authoritarian or directive manner.

Jean referred to an occasion in the hospital when she felt she was being forced to do something and her knowledge as the mother of the baby was being ignored. She seemed to perceive this to be disempowering or undermining her role. Jean seemed to recognise the importance of her role in her infant’s life and did not feel that it was being respected by others.

M: ...cause this nurse says eh it's time to feed your baby and I says “but she'll no take it if you wake her up. I says you have to leave her herself to wake up and I says you can try her, you wake her up, and you'll find out,” so I woke her up and tried but she wouldnae take that

bottle. *“That’s what I tellt you, you got to leave her and let her wake up herself”. They tried to force us I says “dinnae force me”*

T: Uhuh

M: I’ll leave me bairn as long as she wants to sleep. (p7, 323,, Jean)

When support was perceived to be given in a manner that disempowered participants, it seemed to lose its value and was no longer regarded as helpful.

She was a bit like she would nae so much support, she would be telling you what to do. You should do this with the child and you shouldn’t do that with your child type of thing. (p17, 803, Ruth)

They were interfering, telling me what to do with Mary the whole time. (p8, 396, Jacinta)

They were telling me stuff to dae and how to dae it and I was getting quite snappy wi them, cause I was like, have you got kids of your own, no, well don’t tell me what to dae then. (p11, 516, Donna)

The disempowering impact this had on the participants’ sense of competency led to confrontational responses on the part of participants. Donna, in this excerpt, discredits the professional on the basis she had no children of her own. This was perceived as an obstacle to having a proper understanding and knowledge of child-rearing by Donna and another mother who through making such a comparison may have sought to increase their own self-esteem.

For some participants the impact of having people tell you what to do also meant that they avoided receiving the support and were more inclined to continue adopting their own methods.

I says “get out” I know what I’m doing. (p10, 491, Jacinta)

Ruth describes the approach taken by another professional who seemed to adopt a more collaborative approach in delivering advice. It seemed that this professional acknowledged the importance of Ruth’s role and this resulted in her being more inclined to follow the advice offered by this professional.

...She’d more advise you, give you, advise you, “you can do it that way, well our way, but em, I would do it that way”, or no so much she would do it, just give us advice other ways we can turn, so if what we were doing wasnae right, we would take her advice on what she would tell us. (p17, 806, Ruth)

All the participants gave examples of times when they felt they were being told what to do by the professionals during the postnatal period. This seemed to have a disempowering impact on participants. It resulted in them no longer perceiving the input of professionals as helpful and, at times, participants actively refused or avoided the support.

4.2.2 Feeling judged

There was the strong sense from participants’ narratives that they felt, at times, as though they were being judged by the professionals involved in their care. This occurred at various

points during the postnatal period. For this one participant it was apparent while she was still in hospital with her new infant.

I knew that when I was in there they would be taking notes and seeing how I am caring for Ross and things cause he was on the register and things so the mid-wives were more involved with me rather than other people cause he was on the register. They were taking notes to feed back to social work on how I was getting on looking after the baby on my own, in hospital, and caring for him and things like that. (p11, 516, Ruth).

This participant, consequently, seemed to feel the pressure of being judged and at times, appeared to place huge pressure on herself to do everything right which, therefore, impacted on her emotional well-being.

Cause you're under so much pressure and people constantly watching you and you've got to do everything properly you had to get it right all the time. So that was a big stress for me. (p14, 689, Ruth)

For other participants, there was the clear indication that they felt they were being judged negatively and seemed to feel under scrutiny from professionals.

Oh you're not changing the baby right, you're not bathing her right and then you're not feeding her right. (p9, 407, Jean)

Luke was starting walking and of course, he's going to fall. He's going to have bruises and things like that. They (the health visitor) were asking how he was getting the bruises from and checking my house was tidy and things like that. (p9, 411, Fiona)

For Fiona, the number of professionals involved seemed greater and their input more intensive. She conveyed the sense that the presence of professionals seemed relentless and seemed to take over her and her family's life.

...as long as they didnae crowd me too much , cause that's what they done, when I had Luke, they were just there in my face all the time, and I could nae cope with it. (p8, 374, Fiona)

This illustrates that feeling judged by professionals for not having done something correctly, led to Donna actively resisting the support. It seemed in the excerpt below that Donna felt she was being judged unfairly by the health visitor involved which fuelled a more aggressive response.

I was changing her bum there and I put the nappy at the sink cause it was a dirty nappy and I was putting the thingy on and like I left the bairn cause obviously she's not going to move and stuff and I left the bairn lying there and I went and got one of those nappy like things and she went "you never done that right! You shouldnae have left her on the floor" I was like "She aint going to move for crying oot loud" and I chucked her oot my hoose. (p16, 771, Donna)

Another participant perceived the negative judgements she received from professionals as a criticism of her parenting ability.

(by nurses) Yeah, they came in the next day and there was about, there was a load of washing and they was saying that Harry and I never changed Mary and her nappy, I says what's that on the floor? There's about 100 dirty nappies, there's a load there, what you trying to do, make me out to be a bad parent? (p11, 516, Jacinta)

It was conveyed by some participants that feeling judged had positive as well as negative valences.

She says "Jacinta well done for bathing her. I've never seen you do that before. (p5, 246, Jacinta)

She would come and speak to you. You know. You're doing well, you're feeding her, you're giving him what he needs. She was guid. (p14, 704, Betty)

There was the sense that participants, receiving this positive feedback, were reassured that what they were doing was correct and this seemed to have an empowering influence.

M: I'm doing what I'm suppose to do and so that means my child's happy and I can give him everything he needs

T: Yeah

M: It's just reassurance for myself. (p17, 817,, Ruth)

Feeling judged is an inevitable occurrence during this period and it seemed to evoke negative and positive emotions on the part of participants. For some, they felt they were under scrutiny which produced negative emotional responses. For some participants, it meant they attempted to avoid or resist the support. Participants, at the same time, communicated that feeling judged positively offered reassurance that they were fulfilling their mothering role.

4.2.3 Significance of feeling understood

It emerged from the narratives of two participants that feeling understood by professionals was important. They appreciated having information presented in a manner that was tailored to their needs.

T: Right ok so that's interesting, you felt you could understand her (midwife)?

M: And she could understand me,

T: So what did she do, do you think, that made you understand her?

M: Plain. Plain how to speak how to talk, and that's what she was there. (p16, 775, Betty)

I was finding it hard to understand cause of my learning disability, so he drew on a piece of paper wi like the pulses. (p12, 571, Ruth)

For both mothers, the issue of feeling understood emerged in hospital where complications arose regarding their infants' health and they were having difficulties understanding the problems. It seemed that having the information simplified or written down for others to then explain to them, provided the important function of easing the anxieties of these participants. It seemed for these two participants that they were aware and forthcoming in openly

acknowledging their intellectual disabilities which may have facilitated this process of feeling understood.

Jean, in contrast, referred to an episode in hospital where it appeared professionals did not have an understanding of her needs emphasising the importance of feeling understood. She had to go on a drip as complications arose following childbirth. Jean did not seem to have an understanding of how long the drip would be in place. From her communication, it seemed she had difficulty understanding the concept of time. She reported feeling abandoned and dismissed as a result. She appeared to struggle to assert herself and to establish what was happening which may have reinforced her feelings of abandonment.

... you were only supposed to have that in for a couple of hours, minutes or a couple of hours. I had that in until the next morning and it should have been out. One of the nurses, came and went and says did they no come and take that out I says no, I've had it in all night. (p13, 629, Jean)

A sense of abandonment was also experienced by Fiona who did not feel that the hospital staff responded appropriately to her needs.

M:...I stayed in on the Monday night..eh.. and on the Monday night I was getting really bad contractions and they just left me

T:Uhuh

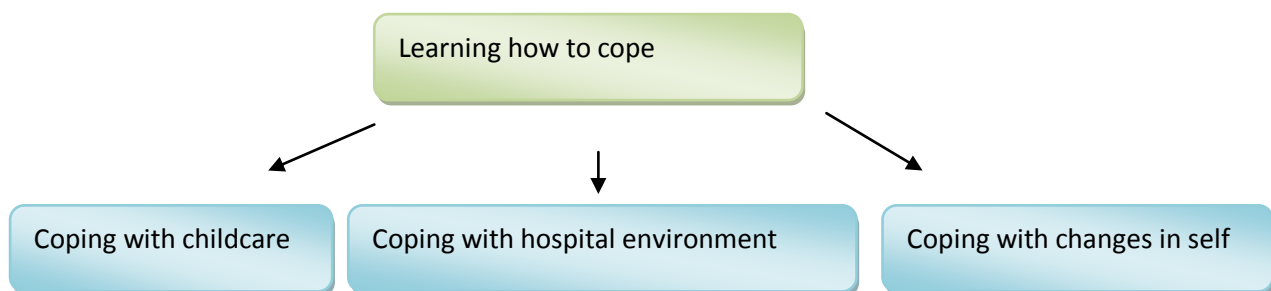
M:the night staff was terrible they just left me lying there in agony.(p2, 51)

It seemed as if this resulted from a lack of understanding as she did not seem clear about what was happening and the reasons why staff were not attending to her. This also appeared to demonstrate her difficulty with asserting her needs.

This subtheme encapsulates the fact that some participants appreciated feeling understood and having information tailored to their needs and that negative implications arose when this was not achieved.

4. 3. Learning how to cope

This super-ordinate theme reflects the resources which parents drew on to cope with their experiences during the postnatal period. There was the sense that these new mothers were learning to cope with the transition to motherhood and trying to develop ways of coping with this new role.



4.3.1 Coping with the childcare

Some participants experienced learning to manage specific childcare tasks as difficult. For instance, two participants found settling their baby to be challenging. Jacinta seemed to have difficulty in responding to the cries of her new infant. This may have reflected a lack of

comprehension or knowledge and she required the assistance of professionals in consoling her infant and identifying an underlying medical cause for her infant's distress.

Well, it was supposed to be one night. But they came often cause I could nae settle Mary cause, she had, she had colic, Harry, and she cannae get her, cannae get her wind away and I was sort of struggling and so they came in to give me a hand cause I was up all night trying to get her wind away and I couldnae get her wind away so they told me she had colic. (p8, 379, Jacinta)

Jean also found it difficult to cope with her infant's distressed cries.

I just gave her a cuddle and that was it, she was fine after that, but it was when you got home eh, late on, that's when it wore off and she was screaming. All the time, and this was when you had to give her calpol. When I was giving Emily calpol she was getting used to it, and when she got used to it she used to greet all the time for it, and I thought nup I cannae keep doing this. (p10, 467, Jean)

Jean seemed to attribute her baby's unsettled state as an indication that she was developing a tolerance for the medicine she was administering. She seemed to have been distressed over the risk of her child overdosing. (It was later revealed that she had not realised her daughter had been teething at the time).

....and then I says well what can I do? Well get the teething powders and I got them and that's what settled, teething powders. (p10, 505, Jean)

Jean still seemed to read the cries of her baby as a sign she wanted more medicine and did not appear to have considered teething as a potential reason for her daughter's distress, even after the discovery of the new teeth and the soothing effect of the teething powders. It seemed that Jean's inability to respond appropriately to her baby's distress was affected by her lack of understanding.

Donna initially stated that she doubted her ability to care for her new infant and this seemed to manifest itself in particular childcare tasks. She disclosed that she was scared of changing her new infant's nappy.

M: She just came along to show me how to bath and things. Like I wouldnae change her bum, like for the first, until that thing falls off the belly, you know where you cut the cord, like I would nae change her bum until that had fell off

T: Why was that?

M: Cos I was scared that I was going to hurt her but then I did try it and I was taking too long you've got to be quick cause they can start getting fed up basically so I had to try and learn how to do it faster. (p8, 368, Donna)

As a consequence, to begin with, it meant that Donna was more likely to seek support from her mother and partner to complete this task. There was a sense that the full realisation of the responsibilities involved in motherhood seemed to overwhelm Donna, suggesting, perhaps a lack of preparation for this role.

I was tired and sometimes I never heard her and that's what I was scared of just, in case I dinnae hear her but then when I got back, when I got out of hospital it just came naturally and I woke up every time she woke up and sometimes I woke up before she woke up cause I got into a routine so it was quite good. (p13, 611, Donna)

Donna conveyed in the above excerpt the benefits of adopting a routine. Ruth, initially, seemed to also doubt her abilities when adjusting to her new role but she also acknowledged that getting into a routine helped.

You've got to meet their needs and the demands of a new child and sleepless nights and coping wi all that, housework and normal day to day routines and that em it was a bit daunting for me. (p13, 611 Ruth)

From the narratives of several participants, there was a sense that they found aspects of childcare challenging. It appeared that feelings of anxiety and self-doubt seemed to fuel these challenges whereas, for other participants, it seemed to be more a lack of understanding.

4.3.2. Coping with hospital environment

Being in a hospital seemed to have a pronounced impact on all participants. Many appeared to have difficulty coping with this unfamiliar social environment. Some participants expressed feeling bored whilst others described feeling lonely without their partner or loved ones.

I felt lonely cause I didnae have John. And I didnae have Lucy. (p3, 159, Fiona)

I think it was just em there wasnae always someone there to keep you company that was the hardest part and being on my own em no-one to talk to well apart from the midwives when they had time. No having my friends or family there wi me, to keep me company, that was the hardest part. (p11, 498 Ruth)

T: So am I right in thinking from what you've said there, that it was maybe a bit lonely?

M: A bit lonely with no one to talk to. (p5, 210 Jacinta)

This seemed to emphasise the reliance participants placed on their family or partner as a main source of support.

Many of the mothers conveyed the emotional impact of being in the hospital through highlighting the benefits of having other mothers to speak to in the absence of visitors or their loved ones.

If you werenae having visitors you were bored. When you've got someone to speak to the time passes that quick. (p12, 559-561 Jean)

It was good, I got to speak to one of the other mums and that who was there as well. (p3, 128-129, Fiona)

It seemed to have been significant to Fiona to have developed a relationship with another mother as she went on to describe how the woman later came to see her newly born infant. She seemed to have been touched by the interest taken in her and her new infant. Fiona

admitted that she was shy and did not seem to find the act of interacting with others straightforward. Socialising with other mothers was evidently more difficult for many of the participants but seemed to be a recognised means of coping with the new environment.

..cause if you dinnae speak to anyone, you do feel lonely and that's when you get quite tearful. So that's one of the things I learnt, tae be brave enough to speak to other people and it did help. (p7, 335, Ruth)

One participant described relying solely on visitors as a means of coping with the hospital environment. The act of socialising with other mothers did not seem to be within the capabilities of this participant.

I dinnae ken anybody, they were all strangers. (p9, 444, Betty)

4.3.3. Coping with changes in self

For half the participants there was a sense that they struggled to cope with changes in their mood during the postnatal period. One participant was given the diagnosis of “the baby blues”. It seemed that coping with this diagnosis was affected by a lack of understanding of what it meant and she drew on the support of her family to help find solutions to her unanswered questions.

M: I had my my sister, but I actually had to travel up to her,

T: Yeah, where's she then?

M: She's up at (place name) , but I was on the phone to her constantly asking her questions, asking her things...

T: What were you asking her about?

M: Just things like, did you have the baby blues and things like that

T: Right

M: She did have them for a while but not as long as what I had it for and she just talked me through things like just do something, keep yourself calm, and just do a crossword book or do something

T: Uhuh

M: And that's what I done, I sat and did a crossword book and that took my mind off things as well. (p10, 486, Fiona)

Donna also seemed to have difficulties with understanding her changes in mood. It seemed that, for her, there were aspects to caring for her new infant that she found difficult. There was a sense that she had not anticipated these difficulties emerging before having her child and had focused on the positive of having someone to care for. This may have potentially contributed to the detachment she describes experiencing.

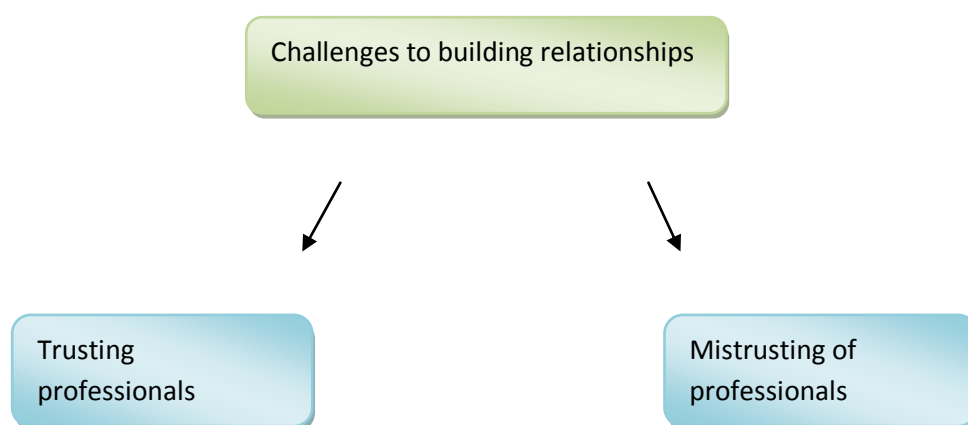
I felt like I wasnae daeing things the way I should be and that. I felt like a bad mum so I kind of detached myself sort of thing I would be upstairs sleeping or going out for a walk without her. I used to go for a walk all the time, I used to take the dog a walk without the bairn. (p14, 656, Donna)

It seemed from what Donna said that it impacted on her ability to respond to her baby's needs.

..cause like, sometimes, I didnae want to hold her, I would just leave her in her bouncy seat thing which I dinnae feel was like a problem cause I dinnae want to hold her 24 7 so she got used to getting picked up and that's what I explained to them cause Jon used to hold her all the time, and then he went to work she wanted picked up by me all the time so I just let her scream in her bouncy chair thing and they says that's fine cause it's no' going to harm her to have her greet as long as she's no greeting hours on end. (p14, 688, Donna)

Jacinta spoke of feeling stressed. Her mood seemed to fluctuate and she would subsequently take it out on her partner. The fact that all the participants had intense involvement from social and health professionals and felt they were being judged, may have affected these changes in mood that participants were struggling to cope with.

4. 4 Challenges to building trust



There were challenges to building relationships with professionals for many of the participants and this impacted on their making effective use of professional expertise. It

appeared from the participants' narratives that trust or lack of trust in professional personnel determined how effectively relationships were forged.

4.4.1 Trusting professionals

Half the participants revealed the importance of trust in their relationships with professionals. Ruth referred to the concept of trust when in hospital and looking after her new baby. She expressed a reluctance to fall asleep as she was concerned that she might awake to find her baby gone. She required reassurance from hospital staff that she could sleep and wake to find her new infant still there. She indicated that it seemed to take a period of time before she could trust the staff but, once she felt this had been established, she was able to make use of their services.

....as the night went on it did obviously I trusted them enough so that I could fall asleep and things like that. (p6, 291, Ruth)

Betty, whilst she was in hospital, also evokes a similar feeling that she could trust the hospital staff who were caring for her.

I think it was cause they were there for you, not behind you, there for us, put it that way. (p8, 395, Betty)

Fiona's narrative indicates that she trusted staff to help her when she was in need.

Furthermore, there was a consolidation of this trust because of the reciprocal nature of the exchange.

She came out a couple of times cause I was getting really bad pains in my stomach and she thought it was contractions as well that I was having..so she was brilliant (p12, 590, Fiona)

Fiona appreciated the professional's belief in her judgement during her pregnancy and this was likely to have had a positive impact on their relationship during the postnatal period particularly as Fiona indicated that there were times when staff doubted the symptoms she was experiencing.

This subtheme captures the concept of trust as an important factor in promoting the development of a positive relationship between professional and parent.

4.4.2. Mistrusting of professionals

Difficulties in trusting the professionals emerged in the narratives of several participants.

Throughout her pregnancy, Ruth had difficulty believing that she would be able to retain the care of her infant and this continued throughout the initial stages of the postnatal period. This was because of her previous experience of having had children taken into care. There was a sense that she felt, before the baby was born, she had a measure of control but, after birth, health and social care professionals would intervene and she would risk losing her infant.

It wasnae until after I started pushing the baby oot I felt a wee bit scared cause still in the back of my mind I felt like this baby was going to be taken away from me basically although I knew, I was told I'd be allowed to keep the baby, but there was still that fear there so. So it was like working towards letting this baby out and all of sudden letting this baby out, it was really scary. (p5, 236, Ruth)

Previous experience of health and social care professionals also impacted on Fiona's view of professionals. She seemed to view them with a general wariness and preferred to limit her contact with these professionals.

The em the only thing with social workers is you need to watch cause half of them can turn the stories around. (p9, 419, Fiona)

When she disclosed experiencing the "baby blues", she did not receive or seek support from social care or health professionals because she did not feel she could trust them. There was a sense from the narratives of two participants that they felt they had been betrayed by professionals.

For Jacinta, this occurred at the hospital just after having had her infant, when members of the social work department unexpectedly arrived. She and her partner were shocked and could not account for who had contacted them but immediately perceived their presence as a threat.

Yes, Harry and I didn't expect any social work to be there and I didnae know who got the social work there. Harry and I are still quizzing. We don't know who got the social works involved. It was a shock! (p6, 275, Jacinta)

Jacinta had not expected their arrival which seemed to imply that the involvement of professionals and reasons for their involvement had not been appropriately communicated to Jacinta. To her, they presented the risk that her child might be taken from her. Even in the company of family, Jacinta and her partner seemed very over-protective of their new infant, but the presence of social workers may have reinforced this over-protectiveness. This seemed to create a barrier for Jacinta to fully collaborate with professionals.

T:...You said, it was a scary thought, that they were there to take your child away. What made you think that?

M: I don't know, it just the thought of them being there and sort of anger inside about who got the social workers involved. It was really scary. (p7, 308, Jacinta)

Jean described a situation where the health visitor expressed concerns regarding her parenting ability and disclosed that she was going to take her concerns to the social work department. This provoked an aggressive response from Jean and she seemed to feel betrayed.

I says (to the health visitor) "look you were awfy awfy nice at first and then you came back and then you says everything I'm not doing righ!"t (p9, 420, Jean)

She no longer appeared to trust the health visitor and consequently requested a change of professional, thereby signalling the end of their working relationship.

It seemed some participants felt betrayed and distrustful of services which impacted on their ability to forge positive working relationships. There was a suggestion that there was a lack of consistent clear communication between the two parties and that a participant's distrust towards professionals often related to previous negative experiences.

5. Discussion

This study aimed to explore the postnatal experiences of mothers with learning disabilities. The analysis of the data led to the emergence of four super-ordinate themes. Each of these themes will be reflected on with reference to the relevant research.

This chapter will also consider the clinical implications of the current findings before highlighting the methodological limitations, potential areas for future research and finishing with reflections on the research process.

5.1. Reflections on 'Challenges of providing support'

Most of the participants appeared to have informal support networks. This corresponds with previous research which has explored the support networks of parents with learning disabilities (Aunos *et al.*, 2008; Kroese *et al.*, 2002). Mothers of participants and partners were identified as the main supports during this period. This is consistent with research which has been conducted with parents at other points in parenthood (Llewellyn, 1995).

Furthermore, this pattern of support seemed to reflect the type of households participants belonged to which has been shown to influence the provision of support (Llewellyn & McConnell, 2002).

In this present study, very few of the mothers referred to friends or neighbours as a support during this period, which is consistent with other studies which have explored the support parents with learning disabilities receive (Llewellyn & McConnell, 2002). The value placed, particularly, on receiving practical support from family, is also consistent with previous research. Kroese *et al.* (2002), who investigated the informal support given to mothers with learning disabilities, identified that there were tasks mothers found harder to complete and

thereby relied on family members for support. The participants in this present study seemed to seek similar support.

In contrast, there were participants who were exposed to unhelpful support from family members. These family members, although recognised as unhelpful, remained actively involved in the care of the new infant. This corresponds with previous research where mothers continued to include unhelpful people in their support networks (Kroese *et al.* 2002; Llewellyn & Bridgen, 1995). Kroese *et al.* (2002) proposed that this might reflect a lack of assertiveness skills on the part of the mother. This appeared applicable to the participants in this present study. There was also the sense that it reflected the greater need for support for these mothers.

Despite a general reliance on members of the family, participants acknowledged the value of advice from professionals and having the opportunity to learn how to care for their infant whilst in hospital and at home. Previous research has highlighted the advantages parents with learning disabilities experience when receiving support from professionals (Starke, 2010). In addition to being offered advice and having questions answered, there was also the emphasis in this present study of participants being shown how to do things. This may reflect the concrete learning styles of this parenting group. Reviews of parent- training interventions have emphasised that interventions which adopted a performance-based rather than knowledge-based approach, were associated with more positive outcomes (Feldman, 1994; Wade *et al.*, 2008). The participants in the present study also valued having someone easily accessible with whom they could talk to and feel supported by emotionally. This echoes the findings of Tarleton and Ward (2007) who found parents valued having support workers they could talk to about issues.

There were two mothers who referred to groups they had attended, one of which was a young mothers' group which ran during the postnatal period. The advantages and personal gains experienced from attending such a group, supports the development of interventions seeking to increase mothers' opportunities to mix and socialise with other mothers (Booth & Booth, 2003; International Association for the Scientific Study of Intellectual Disabilities, 2008).

A recent study describes an initiative which provided pre and postnatal services to young parents, including parents with learning disabilities (McKenzie *et al.*, 2010). Although not developed specifically for parents with learning disabilities, the structure and content of the group was in accordance with recommended practice for this parent group including modelling, repetition and active participation. Attendance was consistently good. The general feedback from parents was that they felt the service legitimatised their parenting role, which was regarded as the most important factor, but they also valued the opportunity to meet other parents and share advice.

Research with mothers in the general population has shown that they view sharing their experiences with other mothers as an important form of support, as well as that received from their own mothers and partners (Darvill *et al.*, 2010; Wilkins, 2010). Wilkins (2010) found that first time mothers actively sought out this support from peers as it helped to normalise the feelings and experiences they underwent during the postnatal period.

The support that mothers in the general population receive could have a bearing on the experiences of mothers with learning disabilities and the challenges that arise. Individuals with learning disabilities, like the rest of the population, have been shown to compare themselves to other social groups (Finlay & Lyons, 2000; Paterson *et al.*, 2009). Research exploring the nature of these comparisons has shown that they tend to make lateral comparisons with individuals without a learning disability (Finlay & Lyons, 2000). In other

words, they see themselves similar in some aspect to a person without a learning disability. Making these comparisons is considered to be protective and maintains self-esteem (Finlay & Lyons, 2000). The tendency for participants in the present study to rely heavily on informal supports post birth may reflect comparisons made to mothers in the general population who typically rely on such supports. Therefore, participants may have regarded this support as more socially acceptable.

The support that mothers received from professionals was viewed favourably, however, when this exceeded what is generally viewed as typical postnatal care, the support was perceived less positively. A possible explanation is that additional support might have led to participants making negative self-comparisons with mothers in the general population. Making negative social comparisons has been associated with poor self-esteem (Dagnan & Sandhu, 1999). The additional support provided by professionals in the present study seemed to disempower and lower the self-esteem of mothers. This may also partly offer an explanation for why mothers preferred to involve unhelpful informal supports in the care of their infant rather than seeking more intensive involvement from professionals.

5.2. Reflections on ‘How support was delivered’

The perception of how support was given by professionals featured strongly across narratives. Many participants seemed to perceive their role as the mother being undermined or dismissed at points during the postnatal period, which clearly had an impact on how they used the support. This is consistent with previous research which revealed the significance of parents’ perceptions of support (Aunos *et al.*, 2004; Llewellyn, 1995). Tucker and Johnson (1989) made an important distinction between “competence-promoting” and “competence-inhibiting” support. Competence-promoting support was observed as support which seeks to enhance parents’ self-reliance and sense of competence in his or her role. Competence-

inhibiting, in contrast, was seen as critical or domineering and thus undermined the confidence of parents. In this present study, 'feeling told what to do' appeared competence-inhibiting as participants no longer perceived such support as helpful. Although this perception of 'feeling told what to do' featured strongly across interviews, it was something which participants related in regard to professionals rather than family. This may have partly contributed to participants' reliance on family members as they felt they were respected and recognised in their central role.

The negative aspects to feeling judged by professionals have been demonstrated in other studies of mothers with learning disabilities (Starke 2010). In the present study it led some participants to feel as though they were under scrutiny. It elicited confrontational responses from participants which, in turn, affected the willingness to accept professional input. The process of being observed could have itself been an unpleasant experience as the mothers were aware of someone unfamiliar and expert watching them undertaking tasks. Wilkins (2010) also reported the discomfort felt by first time mothers at having to demonstrate their developing skills in front of people they perceived to be more knowledgeable. In contrast to this present study, Starke (2010) found that feeling judged also applied to mothers' interactions with family members. This, however, did not seem to emerge in the narratives of participants in the current study.

People with learning disabilities are more likely to have lower self-esteem than those individuals without a learning disability (Crocker & Major, 1989). Research has shown that many people with a learning disability recognise the stigma attached to the label and that this can have a negative impact on a person's mood and self-esteem (Dagnan & Waring, 2004). Cognitive theory proposes that when someone has low self-esteem, they may be more hypersensitive to receiving negative feedback (Beck, 1967). A heightened sensitivity may

have potentially influenced the experiences of participants, contributing to their disclosures of feeling judged and told what to do.

The participants in the study valued the positive feedback from professionals, as it seemed to offer reassurance to participants that they were performing their role satisfactorily and likely to have enhanced their self-esteem. There was also the indication that it helped to forge a positive relationship between mother and professional. Consistent with this, Starke (2010) found that parents valued the aspect of positive feedback as it increased confidence in their role. Research that has been undertaken with mothers without learning disabilities, has shown that reassurance, in addition to the learning of new skills and advice, also contributed to emotional well-being (Wilkins, 2010).

For a few participants, feeling understood and having information presented in a manner that is easily comprehensible emerged as an important factor. This is consistent with Starke (2010) who found professionals did not provide sufficient accessible information to parents with learning disabilities. The need for information to be delivered and adapted to the learning needs of parents has been recognised in recent policies (DOH, 2007; Tarleton *et al.*, 2006) and has implications for professionals working with this client group. Barkby *et al.* (2009) carried out three focus groups involving health visiting teams. They looked at the needs of parents with learning disabilities along with the needs of services in supporting them. The discussion revealed that health visitors felt they had inadequate knowledge about communicating with and supporting parents with learning disabilities.

5.3. Reflections on 'Learning how to cope'

For participants in this study, learning to cope with the transition from home to the hospital environment emerged as a significant issue. Many participants felt the absence of their loved

ones and were eager to return home. This, interestingly, contrasts with a qualitative study in the general population where the transition from hospital to home was a time of increased anxiety as parents left the perceived safety of the hospital to care for their new baby at home (although all the mothers were first time mothers) (Wilkins, 2010). Whilst in hospital, talking to other mothers and exchanging stories was regarded as a positive factor, although it was not something that all mothers with learning disabilities found easy to do. This may relate to the absence of friendships found among parents with learning disabilities (Kroese *et al.*, 2002). This time in hospital was also when most participants valued receiving emotional support from professionals, perhaps another indicator of the difficulties they had in adapting to this new environment. Studies, which have explored the experiences of adults with learning disabilities in hospital, have identified a need for greater empathy and understanding from hospital staff and an awareness of the increasing reliance and need for support at these times (Dinsmore, 2011).

Despite being in receipt of postnatal care from professionals and family, many mothers appeared to have difficulties coping with the various demands of their new role. This seemed to reflect an underlying lack of understanding and feelings of self-doubt and anxiety.

Research which has been carried out in the general population has shown that feelings of self-doubt and a sense of inadequacy are often emotions which affect new mothers as they try to discover the best ways to care for their infants. Darvill *et al.* (2010) found in her study that the self-doubt experienced by first time mothers in the general population was compounded by inadequate and unrealistic preparation for parenthood. In the present study, a lack of preparation pre-birth may have potentially contributed to participants' inability to cope and more preparation regarding childcare may have benefited mothers. This corresponds with research that has emphasised the benefits to parents with learning disabilities to be included

in accessing generic antenatal services (Tarleton et al 2006; Tarleton & Ward, 2007). The effects of learning to cope may be more disproportionate for this population as they may not be equipped with the inner resources to develop effective coping strategies. Research in the general population has highlighted difficulties with organising or re-organising one's life around a new infant as well as the need to have a predictable and manageable routine (Crouch & Manderson, 1993). This is likely to be equally challenging for mothers with learning disabilities. However, there was a sense with a few participants in the current study that, once they had coping strategies in place, for instance, routines, their ability to cope increased.

There were a few participants who struggled to cope with changes in their moods and there was a sense that they had difficulty with understanding what these changes meant. It seemed that they may have been, potentially, related to the scrutiny that participants were under from professionals. These participants did not seem to be receiving sufficient positive, reassuring feedback regarding their parenting ability. For one mother who reported changes in mood, there was a sense that she found carrying out childcare skills harder than she had envisaged. The belief that skills to care for a new infant will spontaneously emerge after childbirth, without training, has been identified as a potential contributing factor to maternal depression (Nicholson, 1998). This may have been a factor for some of the participants in the present study. Little research exists about postnatal depression in mothers with learning disabilities. One mother, however, who was diagnosed with postnatal depression, also reported receiving low levels of support which has been found to raise the risk for postnatal depression in mothers (Cooper & Murray, 1998; O'Hara & Swain, 1996).

Participants may be making negative self comparisons with non-learning disabled peers, triggering or exacerbating the low mood and poor self-esteem experienced by some mothers. Participants may not have been aware that changes in mood and feelings of self-doubt about

managing their new role are not uncommon experiences post-birth, demonstrating a lack of preparation for the role of becoming a mother. There was a significant absence of participants having roles beyond that of being a mother. For instance, no participant was employed or seemed to have a range of social experiences unrelated to their mothering role. It has been proposed that when someone has a variety of roles in life and aspects of the self that they value, otherwise known as ‘complexity of self’, then this helps protect against the effects of negative social comparisons (Linville, 1987). This difficulty with succeeding in other areas of their lives and, the fact that two of the participants had unsuccessfully parented children before having had their more recent child, may also have contributed to the low mood experienced by some parents. Research has shown that previous experiences of failure in the lives of adults with learning disabilities may pre-dispose them to psychological problems (Jahoda, 2006).

5.4. Reflections on ‘Challenges to building trust’

There appeared to be challenges to the building of effective working relationships between participants and professionals. Additional studies have found parents value trust when working with professionals (Starke 2010; Tarleton & Ward, 2007) and that it contributes to building good relationships. Such studies have highlighted the importance of trust being reciprocal and professionals seeming to trust and believe in the participants (Starke, 2010). This appeared significant to one participant in the present study. The influence of previous experiences with services seemed to impact on the abilities of some participants to trust professionals. This is consistent with Booth (2000) who proposed that a lack of trust stemmed from previous negative experiences with services. Although this was largely the case in this study, for one other there was a natural distrust of services combined with what seemed to be over-protectiveness towards her new infant. It seemed that, once participants felt they could

no longer trust the professionals involved and perceived them to doubt their parenting abilities, it was difficult to recover the relationship.

5.5. Reflections on adults with learning disabilities as participants

As indicated in the methodology, conducting qualitative research with adults with learning disabilities presents challenges. Some may have difficulties with complex grammatical phrases, abstract concepts or verbalising responses (MacLean *et al.*, 1996). The participants in the present study demonstrated varying degrees of ability. For Betty and Jacinta, who gave limited responses, prompting was used to facilitate the conversation and the interviewing style was adapted to meet their needs as outlined in the methodology. Also, in line with recommendations from Booth and Booth (1996) the researcher tried to communicate in more concrete terms and avoided questions that related to time and frequency. For participants who had a more concrete frame of reference, it was helpful to check if something had occurred before or after an event as there could be confusion with the sequencing and settings of events (Biklen & Moseley, 1988).

5.6. Clinical implications

The impact that qualitative research is likely to have on understanding an area and its translation into practice is regarded as a decisive criterion by which any piece of research must be judged Yardley (2000). There are several ways in which these findings may be relevant to clinical practice.

The role of the professional in providing support was regarded highly but was secondary to family which was a key form of support for mothers during this postnatal period. This was mainly in providing practical support, particularly child care. Consequently, for professionals working with mothers with learning disabilities, it may be worth giving greater consideration

to the structure and quality of their wider support networks. For mothers who have a pre-existing support network, it may be advisable to try and negotiate with the mother where the professional fits within this established network. For mothers who have a less stable or unhelpful support network, it may be necessary to provide more intensive support to fill the gap.

The value attributed to attending a young mother's group by one participant reinforces the benefits of increasing the opportunity for socialising with other mothers. It is also a means of strengthening parents' resources in dealing with new tasks such as childcare skills. For the participant in this study, the fact that it was a small group helped with the initial stages of attendance. Tarleton and Ward (2007) also recommended that mothers with learning disabilities are supported in accessing generic services such as antenatal classes. Previous research has revealed a discomfort in attending such groups on the part of mothers, as they feel they may appear different from the others (Martin, 2002; Tarleton *et al.*, 2006). Equally, such services may lack the confidence and expertise to accommodate parents with learning disabilities (Llewelyn & Bridgen, 1995; Tarleton *et al.*, 2006). It may be worth considering ways of increasing awareness of or facilitating opportunities for mothers to attend such groups.

Consistent with recent policy on working with this parenting population (DOH, 2007), the present study suggests that professionals during the postnatal period need to consider how they communicate information and advice to mothers with learning disabilities. It is recommended they appreciate it is valued when delivered in a sensitive and non-stigmatising way that acknowledges the importance of the mother's role in the infant's life, particularly when input is more intensive. Furthermore, the perception of how help is given can influence the degree to which mothers engage with services and forge a working relationship. It is

worth trying to adopt a collaborative approach rather than being too directive as this may only succeed in making the mother feel disempowered or undermined. It is important to empower mothers and give positive feedback when possible as this seems to provide essential reassurance and facilitate the building of relationships.

The importance of how information is communicated to mothers with learning disabilities may help to inform the practice of clinical psychologists in both adult learning disability and child services who may be involved in direct work with mothers with learning disabilities, for instance, when conducting parenting assessments. It may also be that clinical psychologists provide a role in delivering training or consultancy to other professionals to facilitate an optimal level of communication and to help develop more effective working relationships with professionals.

5.7. Methodological limitations

One limitation of the study was that it had a sample size of six participants. This reflected two main factors: that many people with learning disabilities may have cognitive and communication difficulties which make participating in research that relies on verbal abilities difficult and that these adults represent just 2.2% of the population (DOH, 2007). For these reasons, they are often excluded from having the opportunity to express their views and, although the numbers are low in this study, it does offer the opportunity for mothers with learning disabilities to communicate their feelings and experiences.

The time lapse from having their last baby varied among the participants and the retrospective nature of the study meant that it was not possible to determine if the participants' narratives accurately reflect the reality of their experiences at the time they had their child. It is possible that participants may have forgotten important aspects or that their

narratives may have been affected by subsequent events. IPA, however, is based on an individual's perception and interpretation of an event and whether it reflects a reality at the time is in some ways irrelevant. It is also worth considering the composition of the participant group. Four of the mothers were interviewed individually and one with her husband present as well as one whose partner was in an adjoining room. This may have affected what was discussed during the interviews.

IPA methodology advises the use of a homogenous sample. However, this sample included some participants who had several children and some who were first time mothers, as well as those who previously had had children removed from their care. It is likely that these different groups have had qualitatively different experiences as well as shared reflections. Future research could explore the impact of such factors on the lived experiences of individuals.

In quantitative research, procedures such as standardised measurement and random sampling are used to ensure "horizontal generalisation" and that findings apply across research settings (Yardley, 2000). The author, in contrast, regards qualitative research as seeking to achieve "vertical generalisation" thereby building on the theory that exists through linking it to the work of others (Yardley, 2000). The researcher has sought to achieve this, to some extent, in this chapter by referring to how the findings relate to existing research. Future studies which adopt a quantitative approach would help to address this lack of generalisability.

The transparency of the study was enhanced by providing a detailed description of how data was collated and analysed and the researcher kept a reflective log to openly reflect on the research process. The rigour, which, according to Yardley (2000), includes the completeness of the interpretation could have been improved by employing the technique of "triangulation". This would have included gathering data from various sources or different

methods. Due to time constraints, the procedures such as multiple coding were not employed which would also have improved the rigour of the study (Barbour, 2001). Coherence in qualitative research, according to Yardley (2000), refers to the “fit” between the research question and the method of investigation and analysis undertaken. This was maintained by allowing the researcher’s supervisor to check sections of transcript and the coding process.

5.8. Future research

Whilst this study explored the view of mothers, it would be interesting to gain a further understanding of the experiences of fathers or partners, especially as they were shown in the present study to play a pivotal role in providing support for mothers. There seems to be little research exploring the views of fathers with learning disabilities (DOH, 2007). It would also be helpful to explore the experiences of professionals who provide care to mothers with learning disabilities during the postnatal period.

As highlighted in the discussion, the next stage would be to carry out a quantitative study, such as developing a questionnaire which could then be completed by a much larger sample of participants. This would help to determine the level of agreement with the reality of these findings and thus help determine the “horizontal generalisation” of the findings. In other words, the extent to which findings can be generalised to the wider population.

In terms of service based research, it has been identified that mainstream pre-and postnatal services need to be flexible in accommodating parents with learning disabilities. It is recommended that formal evaluations of generic antenatal and postnatal services, which are attended by parents with learning disabilities, would identify in more depth the aspects which are valued by parents. It would also help to determine the extent to which such groups influence factors such as family stress and knowledge and skills.

5.9. Reflections on the research process

In this section, the researcher openly reflects on her own assumptions, intentions and actions and her interactions with participants as a researcher. As highlighted in the methodology, reflecting on the process is seen to enrich the quality through increasing transparency and coherence (Yardley, 2000).

Since studying on the Programme, I have continued to work with adults with learning disabilities in a clinical setting, including working with parents. This has raised interesting issues in terms of service provision for this population as well as those perceived by parents. Motivated by my work with this particular population and the increasing numbers which seem to be coming to the attention of services, I looked to explore this area further. In consultation with my supervisor, a question and aim were identified.

My training has been mainly Cognitive Behavioural Therapy (CBT) focused. Whilst I employ such techniques, I tend to be less directive and more person-centred. This was my first experience of conducting a qualitative piece of research which is likely to have impacted on the process. At every stage, I tended to be anxious about doing things the right way but, at the same time, did enjoy having the opportunity to extend my learning in this area.

During the recruitment process, I learned I had to be more proactive and persevering than I perhaps had envisaged. Whilst members of the team were largely keen to assist, one member had concerns about approaching potential participants and adopted a more protective stance. Some of the concerns included the number of professionals involved in the potential participants' lives or that the research process might cause unnecessary distress. This meant that I had to communicate clearly the research process and effectively contain peoples concerns. This, in conjunction with my inexperience in conducting qualitative research,

perhaps resulted at times in my being overly attentive to ensuring participants understood they did not have to take part in the study, rather than equally promoting the benefits.

After completing each interview, I reflected on the content and considered how it might have been improved. I felt that the interview experience contributed positively to my clinical work. It has encouraged me to adopt a more probing approach and alerted me to my over-sensitivity towards the feelings of clients at times. On occasions, people described distressing events. This, inevitably, had an impact on me and it often elicited mixed emotions. I felt I empathised with mothers at such times. It seemed people whom they should have been able to trust and gain support from, instead took advantage of their vulnerability. At the same time, it alerted me to a feeling of concern for the child's welfare, the risk exposed to him or her and the long term effects. Some of the mothers acknowledged that they were aware they would not have their children unless they were in their current relationships. This could result in a power imbalance within their relationships which didn't sit comfortably with me, as it seemed to heighten their vulnerability.

I was conscious of feeling a sense of helplessness and having to accept there was nothing I could do to change things. Or perhaps it was an overwhelming sense of where to begin given the complex issues surrounding peoples' lives. Closely related to this was the process of adjusting to my remit as a researcher which perhaps magnified this sense of helplessness. I was aware, at times, I had to remain within this role and not adopt a more therapeutic stance, especially when parents were clearly misunderstanding situations and reporting psychological problems. I was, however, able to direct them to sources of support in accordance with ethics proposal.

To try and avoid a power imbalance by seeming to be the expert, I encouraged participants to ask me any questions. There were two mothers who were interested to know whether I had

any children of my own. I have not and, as a result, I recognised that I may not have been able to identify to the same extent with the experiences that these mothers underwent. I did not feel, however, that it had a significant impact on the interview process or that mothers were unwilling to share their experiences as a result. I think if it had any bearing on the interview, it may have been that it made them feel they were the experts. One participant, in particular, gave me information which she felt would be useful if I have my own children.

During the initial stages of the analysis, when hearing interviews played back and transcribing them, I was aware, again, of the emotional impact of some of the content. As I progressed through the analysis, I found that I wanted themes to fit neatly into categories rather than them overlapping and being open to different interpretations. I also had to be reminded by my supervisor, at times, to be more interpretative and introduce my own voice rather than remain too descriptive which I think reflected my novice perspective. Although the content of the narratives suggested parents found parenthood a challenge, at times I found myself reluctant to appear to be highlighting examples of poor parenting skills.

All participants had experienced the removal of at least one child from their care by child protection agencies which might have affected the interview process. I felt one mother, in particular, was initially reluctant to disclose anything negative regarding her experiences of parenting. As our interview progressed, however, she relaxed and revealed that there were times when she found her role more challenging which contradicted what she had earlier described. She seemed to feel the need to depict a perfect picture to make clear inadequate parenting skills were not the reason for the removal of her child. I think she was also uncertain to what degree she could trust me. For another mother, it seemed that past negative experiences with professionals meant she presented informal supports in a more favourable

light and was, at points, reluctant to acknowledge any positives about the professional support she received.

Overall, I feel that the process of conducting qualitative research has been a steep learning curve. I felt privileged and grateful to the mothers for sharing their stories. I admired their strength in the face of adversity. At the same time, it emphasised how important being a mother was to them and their commitment to their role.

5.10. Conclusion

This study aimed to explore how mothers with learning disabilities experience formal postnatal care. Findings revealed that informal supports were regarded as a key source of support during the postnatal period and that input from professionals was valued but only when delivered according to the typical pathway of care. Consistent with previous research, participants were concerned with how support was delivered and how this made them feel in their mothering role. Furthermore, the perception of how help was given seemed to influence the degree to which mothers engaged with professionals and forged an effective working relationship.

The findings suggest that consideration is given to how the support is delivered as it should essentially seek to empower parents rather than undermine them so that they are able to use the support offered to full effect.

Despite the limitations of the study, it is a useful stepping stone in understanding the needs of mothers with learning disabilities during the early stages of their parenthood.

6. Journal Article

*This journal article was prepared in accordance with guidelines for the **Journal of Applied Research in Intellectual Disabilities** (see Appendix 14)*

Abstract

Background: There is growing evidence that many parents with intellectual disabilities when given adequate support can parent successfully. This paper aims to explore the postnatal care experiences of mothers with intellectual disabilities.

Method: Six mothers with intellectual disabilities were interviewed about their experiences. The data were collected and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Four super-ordinate themes emerged from the data with accompanying subthemes: challenges of providing support, how support was delivered, learning how to cope and challenges to building trust.

Conclusion: The findings suggest that participants' informal supports play a key role during the initial stages of parenthood particularly with providing practical support in areas which present challenges. Professional input was valued when delivered according to the typical pathway of care post-birth. It is recommended that consideration is given to how the support is delivered to participants. This should essentially seek to empower parents rather than undermine them as how support was perceived impacted on parents subsequent engagement with professionals.

Keywords: intellectual disability, mothers, postnatal care

Introduction

Parents with intellectual disabilities are more likely than any other group of parents to have their children permanently removed by child protection services and placed in care (Booth & Booth, 2005). The first ever national survey of adults with intellectual disabilities carried out in England in 2005 found that 48% of parents no longer had their children living with them (Emerson *et al.*, 2005). Whilst there is no robust evidence to indicate why some parents with intellectual disabilities struggle and others succeed in providing “good enough” parenting, it has been identified that having access to formal or informal social supports may be an advantage for parents (International Association for the Scientific Study of Intellectual Disabilities, 2008). Murphy and Feldman (2002) propose that when given adequate support parents with intellectual disabilities can effectively parent.

Several studies have examined the social support networks of parents with intellectual disabilities revealing the limited support available. Furthermore, the support typically involves family members (Guinea, 2001; Kroese *et al.*, 2002). Kroese *et al.* (2002) who carried out interviews with mothers with intellectual disabilities found mothers naturally relied on the informal support networks for help in areas of difficulty such as shopping and transport to hospital in times of emergency. Mothers also considered support with childcare as one of the most helpful aspects of informal support. Mayes *et al.* (2008) found expectant mothers with intellectual disabilities recognised the need for practical assistance following the birth of their child. Mothers were found to proactively negotiate a support network around them prior to their infants’ births. Furthermore, they found that mothers were careful to ensure they included people who were likely to recognise the central importance of the mother’s role in the infant’s life.

The findings of Mayes *et al.* (2008) and other studies suggest that how parents perceive the support is imperative to support being helpful (Aunos *et al.*, 2004; Tucker & Johnson, 1989). Llewellyn (1995) found that parents did not always feel comfortable with seeking support from professionals as there was a tendency for parents to feel that professionals ignored any difficulty they had in understanding. Tucker and Johnson (1989) made a distinction between support that was “competence-promoting” and “competence-inhibiting”. Competence-promoting support was observed as that which seeks to enhance the parent’s self-reliance and sense of competence in their role. Competence-inhibiting, in contrast, was seen as critical or domineering and thus disempowering parents.

There is a small but evolving evidence base focusing exclusively on parents’ experiences of formal support (e.g. Booth & Booth, 2005; Tarleton & Ward, 2007). Tarleton and Ward (2007) interviewed a cohort of thirty parents with intellectual disabilities to examine their experiences of positive support from professionals and service providers. Parents identified types of emotional and practical support which enhanced their ability to develop parenting skills such as feeling listened to and receiving help with learning new skills. A more recent study by Starke (2010) explored the views and experiences of seven Swedish mothers with intellectual disabilities in their encounters with different health and social service professionals. The author found three distinct themes emerged from their interviews. Firstly, a lack of comprehensibility was experienced by mothers during their interactions with support workers, resulting from a lack of information and a perception of not being treated properly. For instance, feeling blamed and judged. Several of the mothers, however, reported receiving support that benefited their parenting abilities. This was felt to be empowering. Thirdly, mothers perceived themselves as subjects needing support.

Childbirth is a significant life event and one that marks a woman's permanent transition to motherhood. The postnatal care a new mother receives is important in facilitating this transition by providing a supportive environment for both her and her child to thrive (Demott *et al.*, 2006). The postnatal period is, crucially, a time when parents first learn to nurture their child. Given that childcare is identified as a potential area of support for parents with intellectual disabilities (Kroese *et al.*,; Tarleton & Ward, 2007), it has been emphasised in recent guidelines that parents with intellectual disabilities be supported in accessing generic postnatal services (DOH, 2007; Tarleton *et al.*, 2006).

It remains unclear whether the needs of new mothers with intellectual disabilities are being successfully met during the postnatal period. It has been suggested that they may experience undiagnosed mental health problems (Cotson *et al.*, 2001; O'Keefe & O'Hara, 2008).

O'Keefe and O'Hara (2008) have emphasised that mothers with intellectual disabilities experience more severe depressive symptoms. However, research, employing the Edinburgh Postnatal Scale routinely used to diagnose postnatal depression, suggests that this may not be a reliable instrument when applied to this population (Gaskin & James, 2006).

Despite this pivotal time of re-adjustment for mothers with intellectual disabilities, there has been, to the researcher's knowledge, no research exploring their experiences of service provision during the postnatal period. To fill this gap in research, this study aims to explore how mothers with an intellectual disability experience postnatal care.

A phenomenological methodology using Interpretative Phenomenological Analysis (IPA) (Smith, 1996) seemed the most appropriate approach, as it explores the understanding of the quality and texture of an individual participant's lived experiences. An increasing number of studies of adults with intellectual disabilities, including parents, have adopted an IPA methodology (e.g. Baum & Burns, 2007; Mayes *et al.*, 2008).

Method and materials

Participants

Six mothers with intellectual disabilities participated in the study. The mothers were aged between 20 and 55 years. All mothers were known to a community learning disability team (CLDT) comprising social care and health professional staff based within a rural population. Two mothers were single and three mothers currently lived with a partner. One other mother was married and lived with her husband. All of the mothers had experienced one or more of their children being removed by child protection agencies. For two of the participants, this was the only child they had. The other participants had between 2 and 8 children. The ages of the participants' youngest children ranged from 10 weeks to 15 years.

Procedure

Permission for the study was sought from University and NHS Ethical Committees. Following approval, potential participants were identified and initially approached by someone in the CLDT who was familiar to them, to see whether they were interested. If so, permission was sought for the researcher to contact and arrange an initial screening interview with the potential participant. Mothers who were identified had an intellectual disability and had previous or current contact with the CLDT. During the screening interview, the author provided the potential participant with more information regarding the nature and purpose of the study. This included talking through an information sheet with the participant in an accessible format. During this process, potential participants were assured of confidentiality and the limits of this. Participants were informed that they could withdraw at any point.

Interviews

A semi-structured interview schedule was used flexibly to enable the natural exploration of mothers' experiences of postnatal care. The participant was reminded that the interview was about hearing her story and there was no right or wrong responses to the questions asked.

After it was initially established how long ago it was that the participant had had her child, the researcher then asked "tell me about having your baby". The researcher adopted a "self-developing" technique (Booth & Booth, 1996). This meant the communication was adapted as required as the interview progressed in response to difficulties that arose. This included employing prompts to probe participants' responses and asking more questions. The interviews lasted for between 57 and 69 minutes. Four of the interviews were conducted in the participants' homes and two in the health centre.

Data analysis

The analysis of the data adhered to the process outlined by Smith *et al.* (2009). Each interview was transcribed verbatim with the mothers being allocated a pseudonym. The reading and re-reading of the data was carried out which facilitated the process of taking exploratory notes and emerging themes. Possible connections between themes were explored to produce clusters of themes. The emergent themes were intended to reflect not only the participant's experience but also the researcher's interpretation. They were seen to capture and reflect an understanding of the participant's experience. In accordance with IPA, the emergent themes captured similarities across mothers' narratives, as well as including idiosyncrasies within the data (Reid *et al.*, 2005). Subsequent transcripts were analysed with a table developed for each transcript. A final master table of super-ordinate and subthemes was produced. The researcher had regular contact with her supervisor and this included reviewing

the coding system thereby conducting credibility checks as recommended by Elliot *et al.* (1999).

The data analysis produced four super-ordinate themes; ‘challenges of providing support’, ‘how support was delivered’, ‘learning how to cope’ and ‘challenges to building trust’. This article will look to focus on the super-ordinate themes of ‘challenges of providing support’ and ‘how support was delivered’ and their accompanying subthemes. Pseudonyms have been used for the names of participants, their respective partners, relatives and children to ensure confidentiality.

Results

Challenges of providing support

Whilst the aim of the study was to explore mothers’ experiences of formal postnatal care, family members appeared to emerge as a key form of support during this period. All of the mothers spontaneously referred to family or significant others as providers of support in their lives, even when the support given was at times unsatisfactory. It seemed, from the mothers’ narratives that input from professionals was valued, however, it was generally considered secondary to that received from family members and its value seemed limited to the care typically received from the mid-wife and health visitor post-birth. There was the suggestion that providing more intensive input could present challenges.

Significance of family support

The support provided by loved ones, particularly by mothers of participants or their partners was clearly significant during the postnatal period. Different types of support were experienced, however, the value of these varied. Instrumental support such as help with

material goods and emotional support were regarded as beneficial but most participants focused on the value of practical support.

If he's there we have turns about feeding. Em, if I'm eating my breakfast John (partner) will take over, like with everything like I'm having my lunch and even at tea time, he'll do stuff as well like he'll put the dinner on and I'll see to Fraser and things like that. It's much easier with John being there. (Fiona)

She (her mother) came and helped us and dressed him, looked after him and like. (Betty)

The value of sharing practical tasks with her partner including housework and childcare, seemed to feature strongly throughout Fiona's narrative suggesting this was something she needed assistance with. Betty more explicitly highlighted her need for support. It's clear that she felt that she benefited from her mother's experience and knowledge of how to perform childcare tasks. Her mother seemed readily available, more so it seemed than her partner.

M: Well she had all the knowledge

T: Yeah

M: about what to do and all that. I done it myself. I done it a lot myself you know but she was good, she was great that way. (Betty)

For two of the mothers, family members played a role in providing instrumental support. One mother, affected by monetary constraints, reflected on the financial support she received from family. Fiona, in contrast, appreciated the supply of clothes.

She (her sister) helps me out quite a lot with clothes for Fraser. She helps me out quite a lot with them. (Fiona)

There was an indication from mothers that they relied on family members for emotional support. This seemed to feature most prominently in reference to mothers' time in hospital

where the presence of such significant people appeared most meaningful and was at times actively sought. This may have been due to the foreign hospital environment or the need for support during the initial stages of transition to motherhood.

It was nice to have two close people (mother & partner) there that mean so much to me there and to support me so that was really nice. (Ruth)

But at the hospital he (partner) was great. He was holding my hand and stuff like that. (Donna)

Mothers seemed to rely heavily on family, predominantly their mothers and partners to provide support during the postnatal period. This was provided in various ways, but most prominently in practical childcare tasks which seemed to reflect specific areas of difficulty for the participants.

Feeling supported by professionals

Despite a strong emphasis on the support from family and loved ones emerging from participants' narratives, the value of professional advice was recognised by them all.

Cause if you ever asked a question, they would tell you what to do and show you what to do but that was it. They wouldn't say you're doing wrong or that. (Jean)

The significance of being shown what to do seemed prevalent in many of the mothers' accounts suggesting it was important in facilitating the learning of childcare tasks.

One of the midwives, one of the nurses, she gave me a hand and showed me what to do, like bath her. (Jacinta)

Cause it was my first kid you know, you want to learn and what you learnt was by watching you know, seeing what she did. (Betty)

Well before I had Lucy she would show us the birthing pool and things like that around the hospital, and talk to us about when it came to the weaning and that as well and just things like that. She was brilliant. (Fiona)

Fiona valued an antenatal group she had attended run by her midwife. Another mother spoke about attending a young mothers group during the postnatal period and appreciating the opportunity to gain professional advice and extend her knowledge of practical childcare.

So we talk about weaning, what's good for them what's bad for them and things like that. We do some cooking and things like that, general discussion if we've got any worries about the baby, cause obviously there's a midwife there and you can ask questions and things like that. (Ruth)

Attending this group also appeared to provide Ruth with additional benefits. She appreciated having the opportunity to meet and socialise with other local mothers and, subsequently, felt that her confidence had grown. She appeared to have been apprehensive about attending this group, but the fact it was something that she had agreed to do before her infant's birth, gave her the impetus to do so. It seemed, from what she communicated, that the small size of the group had also facilitated her engagement.

Em I'm not as shy now, I can em, like if I don't know someone, I've got more confidence to actually speak to them rather than shy away from that person and try and engage wi' them. Whereas before, if I didnae ken someone I wouldnae talk to them and I would sit in the corner and things. (Ruth)

There was the sense that the advice from professionals was appreciated by Donna but more so when she could see that it was important. This implies there were times when she perceived the support provided by them as less important or its value less clear or easily understood.

It was different with Mary cause she was cold. You had to have the water a certain temperature for the bairn for a couple of months or something and I dinnae mind them coming in and daein that cause that was important. (Donna)

This task may have been considered to be of particular importance as it was something which both Donna and her partner had found difficult to perform.

Half the participants conveyed the sense of feeling they had someone they could talk to and from whom they could gain some form of emotional support. This tended to be the midwife, who was most involved in their care.

If you were upset like, Emma (midwife) was there to talk to. (Fiona)

I got a bit tearful and things like that and one of the midwives took me away to another room, spoke to me, gave me a shoulder to cry on. And things like that, so it was really good. It was nice that they actually did that and listened to me, let me get it all out basically. (Ruth)

Betty also seemed to feel that her midwife made herself available, but it also appeared significant to her that the midwife was empathetic to her situation in becoming a new mother.

..cause she knew what I was going through cause it was my first kid you know. (Betty)

Although it seemed greater emphasis was placed on the practical support from professionals, a number of participants still appeared to value feeling cared for emotionally and having someone who was accessible and empathetic to their situation. This tended to be someone who had most regular contact with the mother and was more familiar.

Perceiving professional input as an intrusion

Despite seeming to value the support from professionals, four of the participants had experienced more intensive input after the birth of at least one of their infants. From their

narratives it seemed that when support was more intensive and exceeded the standard pathway of care, it was viewed less favourably and the presence of professionals seemed almost relentless.

They were in and out like yoyo's (p8, 380, Fiona)

T: And was there staff there?

Yeah, every five minutes, they were always interfering, I says "get out", I know what I'm doing (p10, 488, Jacinta)

The continued presence of professionals seemed to have a negative impact on the life of participants as implicated in the excerpt above by Jacinta. It seemed as if the presence or continued input of professionals lowered mothers' perceptions of their own capabilities. As a result, Jacinta ended up trying to resist receiving the support and a similar suggestion of the negative affect was demonstrated by other participants.

..It wouldnae have bothered me to have them there as long as they didnae crowd me too much, cos that's what they done.....there in my face all the time, and I couldnae cope with it (p8, 374, Fiona)

So basically that's why I came back here early (to her own house) to get away from them all (p12, 559, Donna)

For Ruth, it seemed that the continued involvement of social work was identified as particularly unhelpful. It seemed that they were not seen as doing something helpful as in providing something tangible. It seemed that their visits were regarded as an unwelcome intrusion which induced a similar sense of disempowerment in their own role rather than seeming to make them feel supported.

They don't really do anything, I don't ken if it's support to be honest wi you cos all they do is come in saying "Hi-ya, how's you? How is the baby? How are things between yourselves?" things like that I don't see that as a support, cost that's just normal chitchat (pause) cos like for me, if we were stuck with money or something and they could like give us a loan of money something, that's supporting us, not actually just saying "hi-ya how's you?" I don't think that's support at all (Ruth, p16, 758)

More intensive input seemed to elicit negative responses from participants and, by some, it was met with resistance.

Managing unhelpful supports

It appeared from the narratives of several participants that they continued to include unhelpful informal supports during the postnatal period. Jean seemed to feel that she suffered as a result of the absence of practical support. Although she had a partner at the time, he did not seem to offer any support with caring for their new infant and Jean clearly felt frustrated by this. From Jean's account, she did not seem to be able to be assertive with her partner and appeared to be in a relationship where she avoided any confrontation.

...cause he (her partner) wasnae helping us ken he was just sitting watching telly and everything. He wouldnae feed the bairn or change the bairn, he would just sit and watch sport all the time. (Jean)

Donna felt that, although she had a partner and family who were willing to help with the child-care, the quality of the support varied.

...cause I wouldnae let (partner) bath her cause when (partner) bathed her one time, he made the water far too hot, and when he pulled the bairn out of the bath she was all red and he burnt her. So I had to buy some cream for the burns and stuff and then I still, for quite a bit I wouldnae let him do nought with the bairn cause of that. (Donna)

Although Donna stated that she would not accept any further help from her partner, there was an indication from content revealed later in the interview that he remained actively involved in the care of their new infant. The fact Donna remained reliant on her partner's support, despite its quality, may be seen as an indication of how much she needed the help to fulfil her mothering role. This need for support similarly extended to her brother on whom she continued to rely even when she was unable to supervise him.

...he went, he took my bairn to the pub, and I wasnae happy wi' it cause she was only a couple of weeks old and em so, what I done was I wouldnae let him take her anywhere unless I was wi him. (Donna)

There was a sense from Donna's interview that she seemed to have difficulty asserting herself with her brother who seemed to almost intimidate her at times. This could potentially have contributed to the reason for his continued inclusion in the care of her infant. For Jacinta, the difficulties which her partner seemed to have with child-care on occasions were disguised through the use of humour.

M:.....one time I bathed Mary when Harry was in and I was laughing you put on a nappy and put it on the wrong way round (laughing), it was funny. (Jacinta)

It seemed that she was reticent to convey any sense that they were struggling. Instead she was focused on communicating the idea of being part of a perfect family unit.

Some participants seemed to rely heavily on informal supports even when they recognised this support was sometimes questionable.

2. How support was delivered

It emerged from all participants' accounts that how they perceived support to be delivered by professionals was a significant issue. Many of the participants identified positive and

negative practices on the part of professionals during the postnatal period which seemed to impact on their experiences of care.

Feeling ‘told what to do’

Feeling ‘told what to do’ by professionals emerged across the narratives of all mothers. It seemed that mothers felt being given advice in an authoritarian, direct manner, disempowered or undermined their confidence in their own abilities to parent.

Jean referred to an occasion in the hospital when she felt she was being forced to do something and her knowledge as the mother of the baby was being ignored. She seemed to perceive this as disempowering or undermining her role. Jean seemed to recognise the importance of her role in her infant’s life and did not feel that it was being respected by others.

M: I says you have to leave her herself to wake up and I says “you can try her, you wake her up, and you’ll find out”, so I woke her up and tried but she wouldnae take that bottle, “that’s what I tellt you, you got to leave her and let her wake up herself”, they tried to force us I says “dinnae force me”

T: Uhuh

M: I’ll leave me bairn as long as she wants to sleep. (Jean)

When support was perceived to be given in a manner that disempowered participants, it seemed to lose its value and was no longer regarded as helpful or supportive.

She was a bit like she would nae so much support, she would be telling you what to do. “You should do this with the child and you shouldn’t do that with your child”. (Ruth)

They were interfering, telling me what to do with Mary the whole time. (Jacinta)

They were telling me stuff to dae and how to dae it and I was getting quite snappy wi them, cause I was like, “have you got kids of your own, no? Well don’t tell me what to dae then”. (Donna)

The disempowering impact this had on the participants’ sense of competency led to confrontational responses on their part. Donna, in this excerpt, discredits the professional on the basis she had no children of her own. This was perceived as an obstacle to having a proper understanding and knowledge of child-rearing by Donna and another mother. This highlights their lack of understanding about the expertise of the professional.

For some participants, the impact of having people tell you what to do, also meant that they avoided receiving the support and were more inclined to continue adopting their own methods. Jacinta, one such mother, indicated she preferred to fulfil her mothering role independently from professionals.

I says “get out” I know what I’m doing. (Jacinta)

Ruth describes the approach taken by another professional who seemed to adopt a more collaborative approach in delivering advice. It seemed that this professional acknowledged the importance of her role and this also meant that she was more inclined to follow the advice offered by this professional.

She’d more advise you, give you, advise you, you can do it that way, well our way, but em, I would do it that way, or no so much she would do it, just give us advice other ways we can turn, so if what we were doing was nae right, we would take her advice on what she would tell us. (Ruth)

All the participants gave examples of times when they felt they were being told what to do by the professionals during the postnatal period. This seemed to have a disempowering impact on participants. It resulted in them no longer perceiving the input of professionals as helpful and at times, participants actively refused or avoided the support.

Feeling judged

There was the strong sense from participants' narratives that they felt at times as though they were being judged by the professionals involved in their care. This occurred at various points during the postnatal period. For this one participant it was apparent while she was still in hospital with her new infant.

They were taking notes to feed back to social work on how I was getting on looking after the baby on my own, in hospital, and caring for him and things like that. (Ruth)

This participant, consequently, seemed to feel the pressure of being judged and at times, appeared to place huge pressure on herself to do everything right which, therefore, impacted on her emotional well-being.

....Cause you're under so much pressure and people constantly watching you and you've got to do everything properly you had to get it right all the time. So that was a big stress for me. (Ruth)

For other participants, there was the clear indication that they felt they were under scrutiny from professionals.

Luke was starting walking and of course, he's going to fall. He's going to have bruises and things like that. They (the health visitor) were asking how he was getting the bruises from and checking my house was tidy and things like that. (Fiona)

Oh you're no changing the baby right, you're no bathing her right and then you're no feeding her right. (Jean)

For Fiona, the number of professionals involved seemed greater and their input more intensive. She conveyed the sense that the presence of professionals seemed relentless and seemed to take over her and her family's life.

...as long as they didnae crowd me too much , cause that's what they done, when I had Luke, they were just there in my face all the time, and I couldnae cope with it. (Fiona)

I was changing her bum there and I put the nappy at the sink cause it was a dirty nappy and I was putting the thingy on and like I left the bairn cause obviously she's not going to move and stuff and I left the bairn lying there and I went and got one of those nappy like things and she went "you never done that right! You shouldnae have left her on the floor" I was like "She aint going to move for crying oot loud" and I chucked her oot my hoose. (Donna)

The excerpt above illustrates that feeling judged for not having done something correct led to Donna actively resisting the support. It seemed that Donna felt she was being judged unfairly by the health visitor involved, which fuelled a more aggressive response.

Another participant perceived the negative judgements she received from nursing staff as a criticism of her parenting ability.

Yeah, they came in the next day and there was about, there was a load of washing and they was saying that Harry and I never changed Mary and her nappy, I says "what's that on the floor there's about 100 dirty nappies, there's a load there, what you trying to do, make me out to be a bad parent?" (Jacinta)

It was conveyed by some mothers that feeling judged had positive as well as negative valences. It offered an opportunity for mothers to receive positive feedback which seemed to reassure them that what they were doing was correct which ultimately had an empowering influence.

She says "Jacinta well done for bathing her. I've never seen you do that before". (Jacinta)

She would come and speak to you. You know. "You're doing well, you're feeding her, you're giving him what he needs". She was guid. (Betty)

M: I'm doing what I'm suppose to do and so that means my child's happy and I can give him everything he needs

T: Yeah

M: It's just reassurance for myself. (Ruth)

Feeling judged is an inevitable occurrence during this period and it seemed to evoke negative and positive emotions on the part of participants. For some, they felt they were under scrutiny which produced negative emotional responses and for some participants meant they attempted to avoid or resist the support. Participants, at the same time, communicated that being judged positively offered reassurance that they were fulfilling their mothering role.

Significance of feeling understood

It emerged from the narratives of two mothers that feeling understood by professionals and having information tailored to their individual needs was important.

T: Right ok so that's interesting, you felt you could understand her (midwife)?

M: And she could understand me,

T: So what did she do, do you think, that made you understand her?

M: Plain. Plain how to speak how to talk, and that's what she was there. (Betty)

I was finding it hard to understand cause of my learning disability, so he drew on a piece of paper wi like the pulses. (Ruth)

For both mothers, the issue of feeling understood emerged in the hospital where complications arose regarding their infants' health and they were having difficulties with understanding the problems. It seemed that, having the information simplified or written down for others to then explain to them, provided the important function of easing the anxieties of these participants. It seemed they were aware and forthcoming in openly acknowledging their intellectual disabilities which may have facilitated this process of feeling understood.

Jean, in contrast, referred to an episode in hospital where it appeared professionals did not have an understanding of her needs. She had to go on a drip as complications arose following childbirth. Jean did not seem to have an understanding of how long the drip would be in place. From her communication, it seemed she had difficulty understanding the concept of time. She reported feeling abandoned and dismissed as a result. She appeared to struggle to assert herself and to establish what was happening which might have reinforced her feelings of abandonment.

... you were only supposed to have that in for a couple of hours, minutes or a couple of hours. I had that in until the next morning and it should have been oot. One of the nurses, came and went and says "did they no come and take that out?" I says "no, I've had it in all night". (Jean)

This subtheme encapsulates the fact that some mothers valued feeling understood and having information tailored to their needs.

Discussion

The aim of the study was to explore how mothers with intellectual disabilities experience postnatal care. Four super-ordinate themes emerged, two of which were examined in the present study. They were: ‘challenges to providing support’ and ‘how support was delivered’.

In considering the findings in the present study, parallels can be drawn between accounts of mothers in this study and previous studies exploring the parenting experiences of those with intellectual disabilities. The majority of participants appeared to have informal support networks. This corresponds with previous research which has explored the support networks of parents with intellectual disabilities (Aunos *et al.*, 2008; Llewellyn, 1995). The value placed on practical support from family, is also consistent with previous research. Kroese *et al.* (2002), who investigated the informal support given to mothers with intellectual disabilities, identified that there were tasks mothers found harder to complete and relied on family members for support which seemed to similarly apply to participants in this present study.

In contrast, there were participants who were exposed to unhelpful forms of support from family members. Although recognised as unhelpful, they remained actively involved in the care of the new infant. This corresponds with previous research where mothers continued to include unhelpful people in their support networks (Kroese *et al.*, 2002; Llewellyn & Bridgen 1995). Kroese *et al.* (2002) proposed that this might reflect a lack of assertiveness skills on the part of the mother. This appeared applicable to the mothers in this present study. There is the implication that it reflected a greater need for support for these mothers. Although greater emphasis was placed on the practical support offered by family members, participants also

seemed to value the emotional support provided, particularly during their stay in hospital, which is consistent with previous research (Guinea, 2001).

Mothers also acknowledged the value of advice from professionals, mainly relating to assistance with childcare. Previous research has highlighted the advantages parents with intellectual disabilities experience when receiving support from professionals (Starke, 2010). In addition to being offered advice and by having questions answered, there was also the emphasis in this present study of participants being shown how to do things. This may reflect the concrete learning styles of this parenting group. Reviews of parent- training interventions have emphasised that interventions that adopt a performance- based rather than knowledge- based approach are associated with more positive outcomes (Feldman, 1994; Wade *et al.*, 2008). The participants in the present study also valued having someone who was easily accessible to talk to and gain emotional support from. This echoes the findings of Tarleton and Ward (2007) who found parents valued having support workers they could talk to about issues.

There were two mothers who referred to groups they had attended that seemed to impact positively on their child-rearing skills. One of them was a young mothers' group which ran during the postnatal period. The personal gains experienced from attending such a group supports the development of interventions seeking to increase mothers' opportunities to socialise with other mothers (Booth & Booth, 2003; IASSID, 2008).

A recent study describes an initiative which provided pre and postnatal services to young parents, including parents with learning disabilities (McKenzie *et al.*, 2010). Although not developed specifically for parents with learning disabilities, the structure and content of the group was in accordance with recommended practice for this parent group including modelling, repetition and active participation. The general feedback from parents was that

they felt the service legitimatised their parenting role, which was regarded as the most important factor and attendance was consistently good.

Research into mothers in the general population has shown that they view sharing their experiences with other mothers as an important form of support as well as that received from their own mothers and partners (Darvill *et al.*, 2010; Wilkins, 2010). Wilkins (2010) found that first time mothers actively sought support from their peers as it helped to normalise the feelings and experiences they underwent during the postnatal period. In this present study, very few of the mothers referred to friends or neighbours as a support which is consistent with other studies which have explored the support parents receive (Llewellyn & McConnell, 2002).

The support that mothers in the general population receive could have a bearing on the experiences of mothers with learning disabilities and the challenges that arise. Individuals with learning disabilities, like the rest of the population, have been shown to compare themselves to other social groups (Finlay & Lyons, 2000; Paterson *et al.*, 2009). Research exploring the nature of these comparisons has shown that they tend to make lateral comparisons with individuals without a learning disability (Finlay & Lyons, 2000). In other words, they see themselves similar in some aspect to a person without a learning disability. Making these comparisons is considered to be protective and maintains self-esteem (Finlay & Lyons, 2000). The tendency for participants in the present study to rely heavily on informal support post birth may reflect comparisons made to mothers in the general population who typically rely on such supports. Therefore, participants may have regarded this support as more socially acceptable.

The support that mothers received from professionals was viewed favourably, however, when this exceeded what is generally viewed as typical postnatal care, the support was perceived

less positively. A possible explanation is that additional support might have led to participants making negative self-comparisons with mothers in the general population. Making negative social comparisons has been associated with poor self-esteem (Dagnan & Sandhu, 1999). The additional support provided by professionals in the present study seemed to disempower and lower the self-esteem of mothers. This may also partly offer an explanation for why mothers preferred to involve unhelpful informal supports in the care of their infant rather than seeking more intensive involvement from professionals.

Many participants seemed to perceive their maternal role as being undermined or dismissed at points during the postnatal period. This clearly had an impact on how they viewed and used the support offered by the professionals. This is consistent with previous research which has also identified unhelpful forms of support from professionals (Kroese *et al.*, 2002; Tucker & Johnson, 1989). Although this perception of how the support was given featured strongly across interviews, it was something which participants related in regard to professionals rather than family suggesting that relatives respected and recognised the mother's central role.

The negative aspects to feeling judged by professionals have been demonstrated in other studies with mothers with intellectual disabilities (Starke 2010). In the present study it led some participants to feel as though they were under scrutiny. It elicited confrontational responses from participants which in turn affected the willingness to accept professional input.

The mothers in this study valued the positive judgements from professionals as it seemed to offer reassurance to mothers that they were performing their role satisfactorily. There was also the indication that it helped to forge a positive relationship between mother and professional. Consistent with this, Starke (2010) found that mothers with intellectual

disabilities valued positive feedback as it increased confidence in their role. Research that has been undertaken with mothers without intellectual disabilities has shown that reassurance in addition to the learning of new skills and gaining advice, also contributed to emotional well-being (Wilkins, 2010).

Feeling understood and having information presented in a manner that is easily comprehensible emerged as an important factor for a few of the mothers. This is consistent with Starke (2010) who found mothers with intellectual disabilities did not feel professionals provided them with sufficient accessible information. Services may lack the confidence and expertise to support parents with intellectual disabilities (Llewellyn & Bridgen, 1995; Tarleton *et al.*, 2006). Barkby *et al.* (2009) carried out three focus groups involving health visiting teams. They looked at the needs of parents with intellectual disabilities along with the needs of services in supporting them. The discussion revealed that health visitors had inadequate knowledge about communicating with and supporting parents with intellectual disabilities.

Clinical implications

For professionals working with mothers with intellectual disabilities during the postnatal period, it may be worth giving greater consideration to the structure and quality of their wider support networks. For mothers who have a pre-existing support network, it may be beneficial for clinicians to try and negotiate with the mother where they fit within this. For mothers who have a less stable or unhelpful support network, more intensive support may be required.

Consistent with recent policy on working with this parenting population (DOH, 2007), the present study suggests that professionals during the postnatal period need to consider how they communicate information and advice to mothers with learning disabilities. It is

recommended they appreciate it is valued when delivered in a sensitive and non-stigmatising way that acknowledges the importance of the mother's role in the infant's life, particularly when input is more intensive. Furthermore, the perception of how help is given can influence the degree to which mothers engage with services and forge a working relationship.

The importance of how information is communicated to mothers with learning disabilities may help to inform the practice of clinical psychologists in both adult learning disability and child services who may be involved in direct work with mothers with learning disabilities, for instance, when conducting parenting assessments. It may also be that clinical psychologists provide a role in delivering training or consultancy to other professionals to facilitate an optimal level of communication and to help develop effective working relationships between professional and mother.

Limitations

One limitation of the study was that it had a sample size of six participants. This reflected two main factors: that adults with intellectual disabilities represent only 2.2% of the population (DOH, 2007) and that many people with intellectual disabilities may have cognitive and communication difficulties that make participating in research that relies on verbal abilities difficult. For these reasons, they are often excluded from having the opportunity to express their views and, although the numbers are low in this study, it does offer the opportunity for mothers with intellectual disabilities to communicate their feelings and experiences.

IPA methodology advises the use of a homogenous sample. However, this sample included some participants who had several children and some who were first time mothers, as well as those who had previously had children removed from their care. It is likely that these different groups have had qualitatively different experiences as well as shared reflections.

Future research could explore the impact of such factors on the lived experiences of individuals. Although it is not possible to generalize to other samples, the study is useful in trying to understand the postnatal care experiences of mothers with intellectual disabilities.

Conclusion

Despite the limitations of the study, it provides some useful contributions to understanding how mothers with intellectual disabilities experience postnatal care. The findings suggest that mothers' informal supports play a key role during the initial stages of parenthood particularly with providing practical support in areas which seem to present challenges. Professional input was valued when delivered according to the typical pathway of care post-birth. It is recommended that consideration is given to how the support is delivered to participants as this should essentially seek to empower parents rather than undermine them and thus ensure they use the support available to full effect.

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Appendix 1: Author guidelines to Research in Developmental Disabilities

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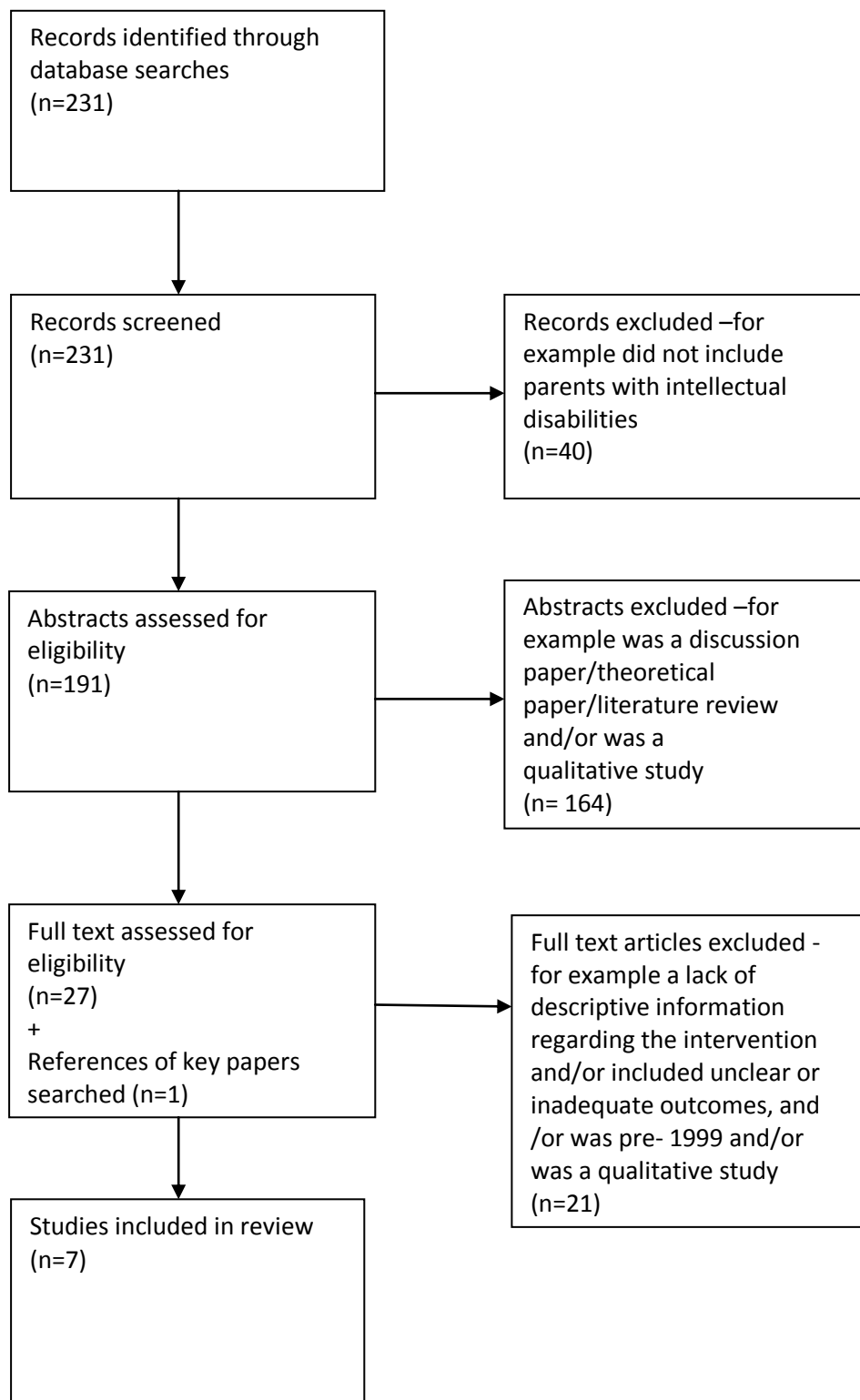
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Appendix 2: Fig. 1. Flowchart of included studies

FLOW CHART OF INCLUDED STUDIES



Appendix3: Table 1: Summary of studies reviewed

Study	n	Parent IQ	Parent age (years)	Child age (years)	Focus of intervention	Training procedures	Intensity of intervention	Experimental design	Quality rating	Results	Maintenance	Drop-outs
McGaw et al. (2002)	22 (14 mothers, 8 fathers)	Experimental Group-mean =73.1 Control group-mean =71.7	Experimental group-Mean=29.1 Control group-Mean=30.4	Experimental Group-Mean=2.4 Control group-Mean=3.3	Social awareness and understanding	Semi-structured format using a CBT curriculum based approach to teaching topics (e.g. recognition of emotions, levels of trust, negotiating skills); parents encouraged to identify thoughts and feelings that reflected real-life relationship scenarios as part of group discussion; parents were taught to identify sequence of ABC's associated with relationship tensions; visual representations were created and used	14 weeks, 2 hour weekly sessions	Between group repeated measures design	-	<p>Judson Self- rating scales</p> <p>Experimental group- -no significant change in “feelings about their children” or “judgements about their children’s capabilities” from baseline, post-intervention and follow-up (p>0.05) significant change in “self-concept” from post-group to follow up (p<0.05) Control group- “judgements of children’s capabilities” significant increase between baseline and post-group (p<0.05) neither group showed significant changes in “interactions with professionals and others” (p>0.05)</p> <p>Social changes questionnaireExperimental group-64% of parents reported positive changes in relationships Control group-none reported</p> <p>BPI Experimental group-no significant changes (p>0.05) Control group-no significant changes (p>0.05)</p> <p>Malaise Inventory No significant differences in reported stress between 2 groups and no change in stress levels across 3 time</p>	27 weeks follow-up period	Not provided

										<p>intervals</p> <p>Single parents-Judson self rating Scales-overall significantly lower ratings of “self-concept” at baseline (p<0.01)</p> <p>Experimental group- “judgements of child’s capabilities” significantly lower at baseline (p<0.05) and post-group (p<0.05)</p> <p>“feelings about your child” and “interactions with professionals and others” significantly lower at post-group (p<0.05)</p> <p>BPI-significantly higher ratings of behaviour problems at baseline (p<0.05)</p> <p>Previous group attendance</p> <p>Experimental group- “judgements of child’s capabilities” and “interactions with professionals and others” significantly higher at follow-up (p<0.01)</p>		
McConnell et al. (2008)	42 mothers	Not provided	Mean=34.1 Range=16.9–48.0	Not provided	Increase confidence and awareness, social integration and social support Decrease depression, anxiety and stress	Problem posing approach rather than a curriculum of skills to be learned; involves a process of reflection on past and present experiences; facilitator supports process and course of action is planned to achieve goals and to put those	Twelve week program; 8-10 week group work phase, supplemented by individual support; approximately two hours in duration for each weekly session	Single group repeated measures design		<p>ASLP Program Goal Achievement Scale-most popular goals were “getting more enjoyment out of life” and “learning more about my own strengths and things that I am good at”, 87% wanting to achieve these “a lot”. Between 90.6-100% achieved goals at least partially</p> <p>Personal Goal AttainmentScale-majority at least partially achieved goals. 84% partially or fully</p>	Not provided	10 (5 prior to group work phase, 5 completed group work phase but no outcome measure)

						into action; three main process: the creation of a “discussion object”, a three step questioning strategy and a stepping stones activity for action planning.				achieved priority one goal. From priorities 2-5, the rate of attainment was 70,88, 82 and 86% respectively IPRI Small effect size for social support (d=0.35) Little effect size for perceived conflict (d=0.08) Scales of Mastery and Constraints Small effect size for mastery (d=0.25) Small effect size for constraints(d=0.25) Depression and Stress Scale Medium effect size for DASS(total)(d=0.50) Medium effect size for depression (d=0.54), Small/medium effect size for anxiety-d=0.40, and stress-d=0.43		es obtain ed)
Feldman & Case (1999)	10 (9 mothers , 1 father)	Not given	Mean=30.33 Range=23-34	Mean=16.5 months Range= 4- 51months	Child care skills: when to call the doctor, when to call 911, preventing suffocation, preventing cuts, burns and bruises, cleaning baby bottles and sterilizing baby bottles	Self-instruction using pictorial manuals based on task analyses; instructed to read the manual asn reading ability, comprehension and motivation to use manual rated; instructed to listen to audiotape accompanying manual; initial prompt given to use manual and audiotape when	NA	Multiple baseline across particip ants		Self-instructional materials effective for 9 out of 10 parents who were taught 11 skills. Mean per cent correct scores increased from 39% in baseline to 72% in training to 86% in follow- up. One parent’s performance failed to reach criterion within 10 visits and required full practitioner-led training. Mean inter-observer reliability agreement was 95%, collected over 12% of the sessions. High consumer satisfaction.	0	0

						carrying out the skill; weekly visits from trainer to observe skill; if no progress after 4 weeks verbal prompt given to use the materials; if after one more week still no progress, parent asked to read manual aloud before observation; if prompts unsuccessful, full practitioner-led training delivered						
Feldman et al.(1999)	10 mothers	Mean=73.8 Range=71-76	Mean=28 Range=19-39	Mean=10.2 months Range=3-22.5 months	Child care skills: diapering, diaper rash treatment, bathing, crib safety, bedtime safety and kitchen safety	Pictorial manuals based on task analyses introduced by trainer; trainer assessed mothers reading ability, comprehension and acceptance of manual; initial prompt given to use manual when carrying out the skill with no further prompts	NA	Multiple baseline across participants		Child-care skills taught with 9 out of 10 mothers, across 12 out of 13 skills. Across 10 mothers, mean percentage correct increased from 56% at baseline to 78.7% with manuals and 90.2% at follow-up (significant at baseline to training and baseline to follow-up, $P<0.001$). Mean inter-observer reliability agreement was 90.8%, collected on 14% of the observations. High consumer satisfaction.	0	0

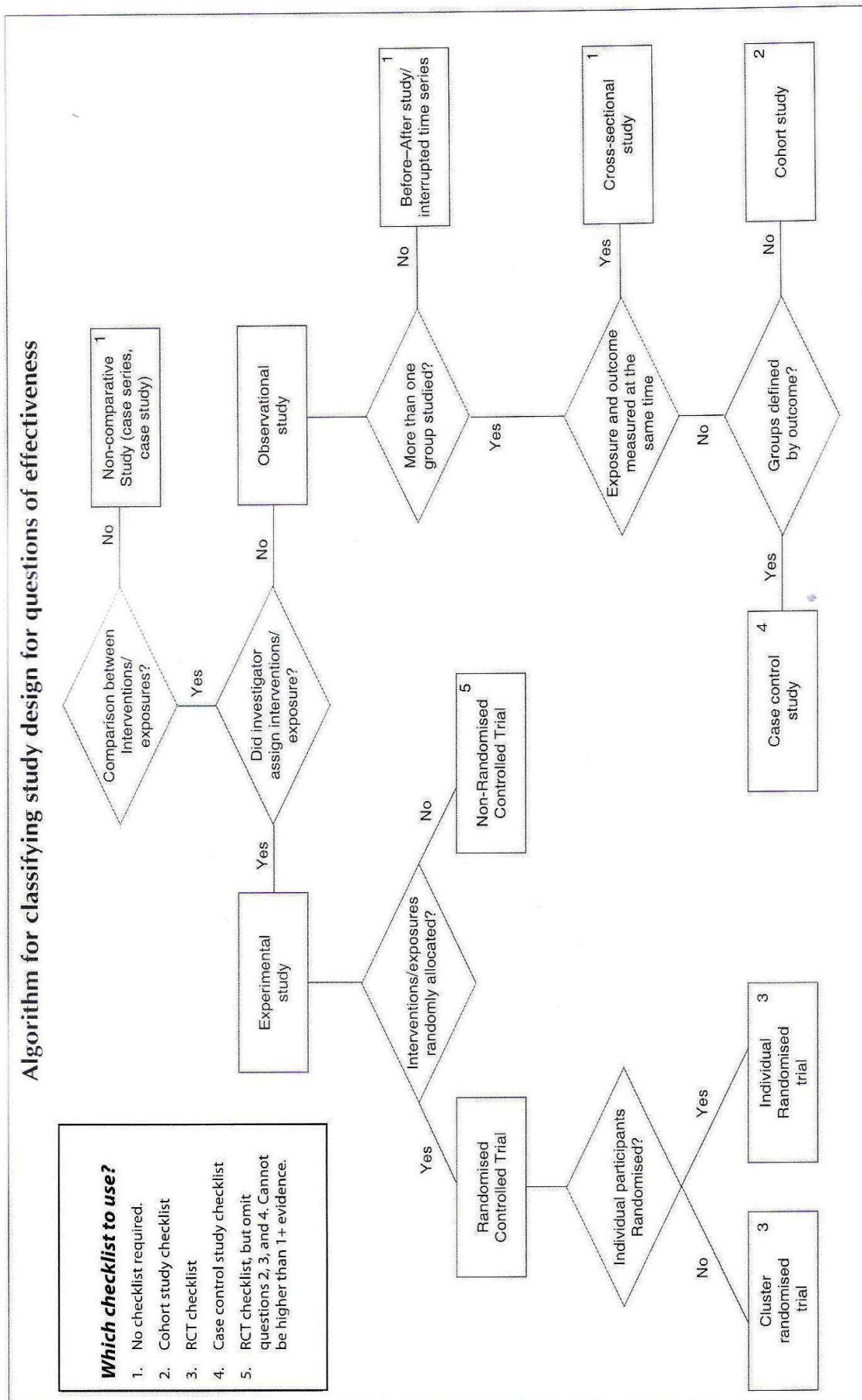
						during training; weekly visits to carry out observation of skill; full practitioner-led training introduced if no progress with manual after four weeks						
Llewellyn et al., (2003)	45 (40 mothers, 5 fathers)	Mean=72.6 Range=40-97	Mean=32 Range=22-45	Mean (of youngest child)=2 years, 4 months Range=0=4 years 6 months	Teaching parents with young children knowledge and skills for managing home dangers, accidents and childhood illness	Home Learning Programme (HLP); curriculum based didactic instruction; trainer worked through illustrated lesson booklet with parents in a one-to one setting; included pictures, questions and activities for the parent to work through; a weekly visit addressed one topic; specific examples from parent's own experience identified and discussed	Weekly sessions were 60-90mins in duration; 10-12 weeks to teach 10 modules	Between groups design with random allocation to groups	+	HLP improved parents ability to recognize home dangers and identify precautions in comparison to all other conditions (p<0.001) HLP parents showed an improvement in the safety precautions they implemented compared with lesson booklet only (p<0.001)HLP resulted in significant improvements in parent's understanding of symptom recognition and illness (P< 0.025 compared with visits and current services and P<0.001 compared with lesson booklets), knowledge of skills needed to manage emergencies (P< 0.0001 compared with visits and current services and P< 0.025 compared with lesson booklets), knowledge about visiting	3 months (n=17)	18 (before or during the baseline assessment phase)

										the doctor ($P < 0.01$ compared with visits and current services) and knowledge and skills about using medicines safely ($P < 0.0025$ compared with visits and current services). HLP parents showed an improvement in health related words and body parts compared with lesson booklet only ($p < 0.01$). Many gains maintained 3 months post-intervention. A decrease from post to 3 month follow-up in home precautions implemented and health comprehension. No inter-observer reliability		
Mildon et al. (2008)	24 (19 mothers, 5 fathers)	Mean=67.58 Range=40-96	MothersRange= 20–49 FathersRange = 30–49	2 years 4 months to 5 years 10 months	Child Care and Home Environment This aimed to facilitate the acquisition and maintenance of good child health outcomes and development, home environment, and home safety. Parent–Child Interaction	Families identified their broad goal for their involvement in the program; specific goals identified with the support of the facilitator; relevant module selected according to these goals and taught specific target skills within that	Weekly sessions for 90 minutes over 6 months (home-based) No. of sessions per family ranged from 10-26 Each session focused on 2-3 skills	Single group repeated measures design (2 parents did not complete the PSOC or ECBI at pre/post intervention)		PDHS -Non-significant differences in mean scores pre-post measures. Significant decrease in the frequency of parenting daily hassles ($d=0.45$) Changes on the PDHS maintained at follow ECBI -non-significant differences in pre-post measures. Significant difference in the intensity of perceived behaviour problems ($d=0.55$) HOME - Non-significant	3 months follow-up period. 4 families (5 parents) did not participate	3 families (4 parents) 2- during pre-intervention assessment

					<p>The content focused on the parent–child relationship by increasing positive parenting and improving children’s social skills.</p> <p>PBS</p> <p>The content focused on teaching parents how and when to use positive strategies to increase child appropriate behaviour and decrease difficult behaviour.</p>	module		tion)		<p>differences in quality of home environment</p> <p>Significant difference in quality of home environment (early childhood version) (d=0.72)</p> <p>At follow-up, changes on the total scores on the Infant / Toddler HOME only maintained. The total score of the Early Childhood HOME decreased slightly</p> <p>PSOC-</p> <p>Non-significant differences in mean scores pre-post intervention in parents sense of competence</p> <p>At follow-up, changes on the efficacy scale of the PSOC were maintained</p> <p>Mean scores on the satisfaction scale of the PSOC decreased slightly.</p> <p>High level of consumer satisfaction completed with 23 parents</p>		
Brisson (2010)	4 mothers	Mean=65.5 Range=58-70	Mean=41.75 Range=37-52	Mean=8.75 Range=6-12	Parental attunement	Communication, Attunement, Responsiveness, Empathy (CARE) to Parent curriculum based programme;	2-3 hour lesson on each of the four modules over a 2-3 week period	Single group repeated measures design		<p>Between group analysis</p> <p>Decreased initiative attunement (d=-0.73)</p> <p>Decreased initiative misattunement (d=-0.69)</p> <p>Increased physical attunement (d=0.76)</p> <p>Within group analysis</p>	0	0

						<p>didactic instruction; trainer worked through series of modules in a 1-1 teaching session; worksheets and activities such as card games and board games included</p>				<p>Family A: Small significant mean increase in attunement ($p=0.03$) Family B: Significant mean increase in attunement ($p<0.001$) Family C: Marginally significant mean decrease in attunement ($p=0.10$) Family D: Significant mean decrease in attunement($p=0.008$) Inter-rater reliability agreement was 86% across all ratings</p>		
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Appendix 4: Fig 2: Algorithm for classifying study design for questions of effectiveness (SIGN, 2008)



Appendix 5: Research highlights

Research highlights

- The paper reviewed interventions for parents with intellectual disabilities designed to strengthen social relationships and to teach parenting skills
- Studies found that group based interventions had a positive impact on social relationships although there were limitations to the studies
- Results for the skills teaching interventions were encouraging and interventions seemed to be effective for some parents
- There was an indication that behavioural based skills intervention can be more effective than less intensive form of input
- No firm conclusions can be drawn from the studies reviewed and a need for larger scale controlled studies is highlighted

Appendix 6: South East Scotland Research Ethics Committee

Lothian NHS Board

Boothby Road

30 DEC 2010

South East Scotland Research
Ethics Committee 2
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 536 9088



www.nhslothian.scot.nhs.uk

Miss Suzanne Wilson
Trainee Clinical Psychologist
Borders NHS
Community Learning Disability Team
Westgrove Annexe
Waverley Road, Melrose
TD6 9SL

Date 29 December 2010
Your Ref
Our Ref

Enquiries to Lyndsay Baird
Extension 35673
Direct Line 0131 465 5673
Email lyndsay.baird@nhslothian.scot.nhs.uk

Dear Miss Wilson

Study Title: Mothers with a learning disability: their experiences of service provision during the post-natal period.
REC reference number: 10/S1102/63

Thank you for your letter of 13 December 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 08 December 2010.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Protocol	1	11 October 2006
GP/Consultant Information Sheets	1	02 December 2010
Response to Request for Further Information		13 December 2010
Investigator CV		11 October 2010
Dr Karen Mckenzie CV		
Participant Information Sheet	2	02 December 2010
Interview Schedules/Topic Guides	1	02 December 2010
REC application	3.0	11 October 2010
Participant Consent Form	2	02 December 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

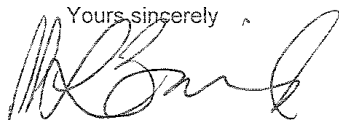
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S1102/63

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

A handwritten signature in black ink, appearing to read 'T Russell', written over the typed name.

Mr Thomas Russell
Chair

Email: lyndsay.baird@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Appendix 7 : Ethical approval from R&D site

NHS Borders

Research Administration
Clinical Governance
Miss Suzanne Wilson

Community Learning Disability Team

Westgrove Annexe

Waverley Road

Melrose

Clinical Office
Borders General Hospital
Melrose
Roxburghshire TD6 9BS

Telephone 01896 826719
Fax 01896 826040
www.nhsborders.org.uk

Date 19 March 2012

Our Ref 10/BORD/32

Enquiries to Joy Borowska
Extension 01896 826717
Email research.governance@borders.scot.nhs.uk



Dear Miss Wilson

Post natal care for mothers with a learning disability

Thank you for sending details of your study to NHS Borders. I can confirm that the Research Governance Committee has reviewed the documentation, and on this basis I am pleased to inform you that this study has management approval for commencement within NHS Borders.

It is a condition of approval that everyone involved in this study abides by the guidelines/protocols implemented by NHS Borders with respect to confidentiality and Research Governance. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek advice if you are unsure.

Please advise the R&D Office immediately of any changes to the project such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Borders.

Amendments to the protocol will require approval from the ethics committee that approved your study. Please inform this office when recruitment has closed and when the study has been completed. Please quote the reference number stated above in all correspondence.

May I take this opportunity to wish you every success with your project. Please do not hesitate to contact the R&D Office should you require any further assistance.

Yours sincerely

A handwritten signature in black ink that reads 'Thomas Cripps'.

Thomas Cripps
Associate Medical Director (Clinical Governance)

Information about the study

Services for mothers with a learning disability

I would like you to take part in my study.

I would like to tell you about the study and what will happen if you take part.

I will go through this information sheet with you.

I will answer any questions you have. This will take about half an hour/30 minutes.

What is the study about?

The study is being done with mothers who have a learning disability.

It looks at the help you get looking after your new baby.

I would like to talk to you about the help you got from services (the people who worked with you) after you had your baby.

About ten other ladies will be asked to take part.

Do you have to take part?

You do not have to take part.

I will tell you about the study.

You do not have to decide if you want to take part now. You will have 24 hours to decide.

If you want to take part, I will ask you to sign a consent sheet.

You can stop taking part at any time. You do not need to tell me why.

This will not change the care/services you get from people in the community learning disability team.

What will happen if you take part?

I will ask you questions. There are no right or wrong answers to the questions.

The questions will help me to understand about the help you got after you had your baby.

I will come back to your house to do the interview or we could meet somewhere else like a health centre.

This will need to be a quiet time in your house.

The interview will last an hour.

You might have questions you want to ask me at the end of the interview.

The interview will be recorded using a digital voice recorder.

Only I will listen to the tape.

The tape will be kept for three months.

It will then be thrown away.

There might be things you don't like about taking part.

Talking about your child or children might make you feel sad.

There might be good things about taking part.

The interview will give you a time to talk and to be listened to in private.

The study might help to change things for other mothers in the future.

Taking part in the research will be confidential.

What we talk about will be confidential. This means that I will not talk about it with anyone else.

I will have to tell people in the community learning disability team if I think you or someone else might be at risk of getting hurt.

I will have to tell someone if I think your child or children might be at risk of getting hurt.

The tape and information will be stored safely so that no-one else can see it.

I will not use your name and no one will be able to tell it's about you.

I might use the research to help other people learn. I will not use your name and no one will be able to tell it's about you.

All information will be kept confidential.

You can talk to Suzanne Wilson (.....) if there is something about the study that worries you.

You can contact George Murray (.....) if you are unhappy about the study and want to tell someone else about it.

This research has been checked by a Research Ethics Committee. They make sure the research is fair.

Thank you for listening.

Appendix 9: Consent Form

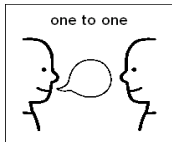
Version 2: 02/12/10

Participant identification number:

CONSENT FORM

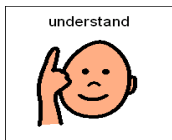
Title of project:

Name of researcher:



1. I have talked about the study and looked at the information

Yes/No



2. I understand what the study is about

Yes/No



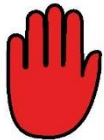
3. I have asked all the questions I want to

Yes/No



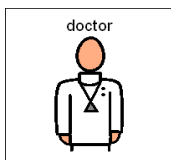
4. I have had all my questions answered in a way I understand

Yes/No



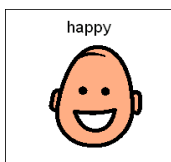
5. I understand that it is up to me if I want to take part. I understand it's ok to stop taking part. I do not have to say why.

Yes/No



6. I am happy for my Doctor to be told that I am helping with the study

Yes/No



7. I will do the study

Yes/No

Your name

Date

Signature

My name

Date

Signature

Appendix 10: Interview Schedule

1. Tell me about having your baby.
2. What was it like being in the hospital after you'd had your baby?
3. How did you feel?
4. Was anything hard?
5. Was there anyone there to help?
6. What did services do?
7. What was it like looking after your new baby at home?
8. How did you feel?
9. Was anything hard?
10. Was there anyone there to help?
11. What did services do?
12. What did they think about how you were looking after your baby?

Appendix 11: Example of analysis

	348	T: So were you almost a bit anxious?	
	349	M: I was nervous,	
feeling nervous	350	T: <u>Nervous.</u>	
	351	M: Aye, mainly nervous, "oh am I going to be doing this right?" and	
	352	stuff like that cos they have to show you how to bath them in the	
	353	hospital and I got to dae it and I was shaking and that. So the mid-	
	354	wife had to take over and then and then in the morning before we	
	355	left, we tried it again and I done it right	coping with child care
	356	T: Good for you	
distrusting self, am I doing it right, pleased with self	357	M: Cos before we left the hospital as well she had to go for some x-	
	358	rays and tests. Cos my mum was disabled, and em, she had to get x-	
	359	rays on her hips and stuff cos my mum had problems wi her hips,	
	360	clicky hips or something, I cant remember, so we were in there for 2	
vague - unsure	361	hours or something, I think it was that, and then they couldnae let	
lack of understanding?	362	us go until they had found out everything was alright,	
let us go	363	T: Ok	
	364	M: And stuff, but everything came back saying she was fine. So that	
	365	was quite good so we got to leave.	
- eager to learn, get home	366	T: Ok, good, so you said it was a mid-wife who showed you how to	
	367	do things?	
concrete advice	368	M: She just came along to show me how to bath and things. Like I	
struggling with childcare - changing the nappy	369	wouldnae change her bum, like for the first, until that thing falls off	
	370	the belly, you know where you cut the cord, like I wouldnae change	
	371	her bum until that had fell off	
	372	T: Why was that?	
challenge of doing it fast enough	373	M: Cos I was scared that I was going to hurt her but then I did try it	
learn how to do it - cope	374	and I was taking too long you've got to be quick cos they can start,	
Feeling scared, scared of hurting her baby: not doing it right	375	getting fed up basically so I had to try and learn how to do it faster	
	376	with the, I cannae mind what that's called, umbilical cord so I	
	377	wouldnae, cos you have to wait for the ? to fall off, cos it falls off	
	378	itself so I wasnae too keen about changing her bum at that stage cos	
	379	I was scared I was going to hurt her. If she didnae have that I would	coping with child care
	380	have been fine but I did manage to do it couple of times.	
	381	T: Good. So they showed you how to do that did they and what else	
	382	did they show you?	
	383	M: That was it, bathing and changing her. That's it, cos I never	
	384	changed her first nappy, it was eh, I let her dad do that. So	
	385	T: So was he there was he?	
lack of confidence - sought practical support from partner	386	M: He, he was there at the birth and that. He was alright like, when I	
	387	was in labour at my mums he was sleeping, and then when his mum	
	388	came along and mum woke him up but he was still nae good. Cos he	
	389	wasnae rubbing my back or nought and every time he came near me	
unhelpful 'til nae good	390	I told him to eff off because he wasnae there in the beginning and	
lack of support from partner	391	stuff. But at the hospital he was great. He was holding my hand and	
	392	stuff like that so em but then cos he had to go he didnae want to go	
	393	cos he wanted to spend more time with his daughter but he	
	394	phoned, I cant remember what he had tae dae but he phoned	
	395	people and said he was going to be a couple of hours late cos he	
feeling supported emotionally	396	wanted a couple of hours wi his bairn which was understandable	
lost my head	397	then he left and then I realised I was going to be on my own at the	feeling supported emotionally

? = recording unclear

8

Appendix 12: Table of the relevance of the four super-ordinate themes and corresponding subthemes for each participant

Super-ordinate themes	Subthemes	Jean	Fiona	Ruth	Jacinta	Betty	Donna
Challenges of providing support	Significance of informal supports	x	X	x	x	x	x
	Feeling supported by professionals	x	X	x	x	x	x
	Perceiving professional input as an intrusion		X	x	x		x
	Managing unhelpful supports	x			x		x
How support was delivered	Feeling “told what to do”	x		x	x	x	x
	Feeling judged	x	x	x	x		x
	Significance of feeling understood	x		x		x	
Learning to how to cope	Coping with child-care	x		x	x		x
	Coping with hospital environment	x	x	x	x	x	
	Coping with changes in self		x		x		x
Challenges to building trust	Trusting professional		x	x		x	
	Mistrusting of professional	x	x	x	x		

Appendix 13: Summary table of individual analyses

Table 1: Summary of analyses of Jean's transcript

Super-ordinate theme	Emergent theme	Excerpt from transcript (page and line number)
Challenges to providing support	Feeling unsupported by partner	<p>cos he wasnae helping us ken he was just sitting watching telly and everything he wouldnae feed the bairn or change the bairn he would just sit and watch sport all the time (p2, 63)</p> <p>M:so I had to feed the bairn , change her, T:Uhuh M:put her doon, dae my housework and he was just sitting no doing nothing (p2, 67) you're doing everything yourself and your getting nae help (p4, 191) I had naebody to gie us a hand (p4, 164) M:I felt tired all the time, having to feed the bairn, T:Uhuh M:then dae the hoose work, do the washing, and you were tired at the end (p4, 169-172) I was just tired all the time (p4, 189) Well I had to feed the bairn, do housework and cook at the same time (p1, 48)</p>
	Feeling supported by professionals	<p>Cos like if you ever asked a question they would tell you what to do (p7, 344) and show you what to do (p8, 347)</p>
How support was delivered	Feeling forced/told what to do	<p>M:...cos this nurse says eh it's time to feed your baby and I says "but she'll no take it if you wake her up". T:Uhuh M:I says you have to leave her herself to wake up</p>

		<p>and I says you can try her, you wake her up, and you'll find out, so I woke her up and tried but she would nae take that bottle, "that's what I tellt you, you got to leave her and let her wake up herself", they tried to force us I says "dinnae force me"</p> <p>T:Uhuh</p> <p>M:I'll leave me bairn as long as she wants to sleep (p7, 323-332)</p> <p>(sister)She turned round and says, you are not going for a fag, you 've got a cooked meal in your belly,(p6, 281) (authoritarian voice)</p> <p>but that was it they would nae say you're doing wrong or that (p8, 349)</p> <p>M:Cos she never interfered cos she just came in to see how you were how the baby were and she watched what you done and you were doing it right (p16, 783)</p>
	Feeling judged	<p>(by hv) Oh, you're no changing the baby right you're no bathing her right, and then you're no feeding her right (p9, 406-7)</p> <p>M:I was but she said I wasnae (p9, 414)</p> <p>M:I felt happy cos some of the health visitors just says you're no doing everything right</p> <p>T:Uhuh</p> <p>M:but she said I was doing everything right (p6, 250)</p> <p>M: She said you're doing everything right. You're keeping your appointments, when you get an appointment you're there, you're there on time. (p9, 438)</p>

		T:I was just happy cos she thought I was doing the right thing ken,(p16, 789)
	Significance of feeling understood	<p>They says if they would nae have put a drip, cos of the clots, cos I lost an awfy awfy lot and you were only supposed to have that in for a couple of hours, minutes or a couple of hours. I had that in until the next morning and it should have been oot. One of the nurses , came and went and says did they no come and take that out I says no, I've had it in all night (p13, 629)</p> <p>if you rung the bell they would nae come or they'd say "We're busy". I mean it was uncomfortable ken sitting like that and losing all that blood and the clots</p> <p>T:Uhuh, yeah,</p> <p>M: it was horrible.</p> <p>T: How did you feel that you were ringing the bell and nobody was coming?</p> <p>M:I just just panicked and I thought oh, they're no bothering,(p15, 703)</p>
Importance of role	Commitment to role	they check you when you've just come out of the hospital to see if you're normal and check the baby and see if you're doing everything right which I was doing everything right but that was it. I kept all appointments I never missed one appointment. I went to them all (p5, 238)
	Preferring to manage independently	They used to show you how to bath and that. I turned roond and I says "look, nobody needs to show me how to bath a baby, this is my eighth baby and I should ken how to bath a baby" aye

		but they were" ah but we have to do this...." (p6, 270)
	Mistrustful of professionals	(by HV) I says look you were awfy awfy nice at first and then you came back and then you says everything I'm not doing right. Have you any kids of your own like? No, well there you go how do you ken? And after that she was fine (p9, 420)
Learning how to cope	Coping with hospital environment	cos if you were nae having visitors you were bored. (p12, 559)
	Befriending other mothers	if you were nae having visitors you were bored. When you've got someone to speak to the time passes that quick. (p.12, 559-561) I wasnae on my own the whole time. T:Uhuh M:and eh the women over the bed so she, there was plenty to talk about. (p1, 41)
	Coping with child-care	M: I just gave her a cuddle and that was it, she was fine after that, but it was when you got home eh, late on, that's when it wore of and she was screaming. All the time, and this was when you had to give her calpol, when I was giving Emily calpol she was getting used to it, and when she got used to it she used to greet all the time for it, and I thought nup I cannae keep doing this. (p10, 467) T: And how did you deal with that then, when she was crying for the calpol? M:I had to tell the health visitor and the health visitor just says look, just give it when she wants,

		but every time you giving it to her, she wants more and more, you cannae cos you cannae do that with a baby. You can overdose. (p11, 494)
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Appendix 13: Summary table of individual analyses

Table2: Summary of analyses of Fiona's transcript

Super-ordinate theme	Emergent theme	Excerpt from transcript (page and line number)
Significance of family support	Feeling supported emotionally	So I phoned John..he came back out on the Monday night ..And I was in tears badly in tears (p2, 60)
	Support with asserting her needs	B: They left me I was sick all over the wee room I was in... A:Were you B:I didnae even have a sick bowl in the room I was in eh...I had no water...John.... had went out and asked them about 5 times to give me water (p2, 95-99)
	Dependency on partner	If I wasnae with John, I wouldnae have Lucy (p7, 327) Well, they told me if John wasnae with me, if he left me, Lucy would have got taken off me from birth (p7, 331)
	value of practical support	It's hard to try and travel with the 2 kids, you need this you need that you need to try and remember things ...like have a got the baby milk, have I got the bottles, have i got the nappies, have I got the wipes, , have I got this, it's hard with the both of them (p4, 706) If it's just me, Lucy and Fraser, I do find it hard cos Lucy wants me to do stuff with her and it's like I have to attend to Fraser as well do his nappy feed him and things like that and Lucy wants wants and I can't do two things at once but it is hard doing it yourself

		(p6, 264) If he's there we have turns about feeding. Em, if I'm eating my breakfast John will take over, like with everything like I'm having my lunch and even at tea time, he'll do stuff as well like he'll put the dinner on and I'll see to Fraser and things like that it's much easier with John being there (p7, 304)
	value of instrumental support	(sister) she helps me out quite a lot with clothes for Fraser she helps me out quite a lot with them ...(p14, 702)
Coping with hospital environment	Feeling lonely in hospital	I felt lonely cos I didnae have John. And I didnae have Lucy. And I missed Lucy (p3, 159) I think it was just about not having Lucy and John there ken I think that's why I got a bit lonely. (p4, 159)
	Befriending other mothers	It was good I got to speak to one of the other mums and that who was there as well (p3.128-129)
Challenges to building trust	Cautious/wary of services	I didn't really want help cos I knew what I was doing cos like with having the rest of them, I knew exactly what I was doing (p4, 193) Did they offer you help? B:Yep, but I just did it on my own. A:Ok, what kind of things did they offer to help you with? B:Bathing, drying, well, I've had four kids, this is the fourth one I've had, and I know what I'm doing but they did ask me but I turned them down. A:What were they like about that? B:They were fine. (p4, 200)

		<p>A:Yep, And were you able to talk to anyone else about the fact you had the baby blues?</p> <p>B:Nope.</p> <p>A:Right. So em you did nt talk to the health visitor or (interrupted)</p> <p>B:I could nae cos I felt that they were all gang up on me....</p> <p>A:Right, so am I right in thinking it was just your GP and your sister?</p> <p>B:Yep</p> <p>the em the only thing with social workers is you need to watch cos half of them can turn the stories around (p9, 419)</p>
	Feeling believed in	<p>She came out a couple of times cos I was getting really bad pains in my stomach ..and she thought it was contractions as well that I was having....so she was brilliant (p12, 590)</p>
Coping with changes in self	Making sense of her baby blues	<p>B:I was upset. angry. I just wanted them all to leave me alone, I just felt, I actually felt like I was going into a dark hole, and just covering myself up..(p10, 454)</p> <p>B:I had my my sister, but I actually had to travel up to her,</p> <p>A:Yeah, where's she then?</p> <p>B:She's up (place name), but I was on the phone to her constantly asking her questions, asking her things...</p> <p>A:What were you asking her about?</p> <p>B:Just things like, did you have the baby blues and things like that</p> <p>A: right</p>

		<p>B: she did have them for a while but not as long as what I had it for and she just talked me through things like just do something, keep yourself calm, and just do a crossword book or do something</p> <p>A:Uhuh</p> <p>B:and that's what I done, I sat and did a crossword book and that took my mind off things as well (p10, 486)</p>
	Feeling socially isolated	<p>B:It was horrible. I had no friends. Eh I had no family, eh well my auntie she had moved up here but she had stopped talking to me, so I didnae have her around..</p> <p>A:Right ,</p> <p>B:I had no friends at all except (name) and (name), they were the only friends I had,</p> <p>A:ok</p> <p>B: I Had no one else around me..</p>
Feeling supported by professionals	Feeling cared for	if you were upset and like Emma was there to talk to.(p12, 581)
	Learning from professionals	(mid-wife) well before I had Lucy she would show us the birthing pool and things like that around the hospital, and talk to us about when it came to the weaning and that as well and just things like that. She was brilliant. (p12, 586-593)
How support was delivered	Feeling judged/under scrutiny	(by hv) Luke was starting walking and of course, he's going to fall he's going to have bruises and things like that they were asking how he was getting the bruises from and checking my house was tidy and things like that, that's what really annoyed me, my house was always tidy when I

		<p>had Luke , always tidy (p9, 411)</p> <p>I brought up Luke the day he was born until the day he got taken off me..em, and the health visitor she was just like saying that Luke was losing weight, which he was n't, Luke was down at the doctors all the time with urine infections, em, and things like that and she got in touch with the social work department and told them "(name)'s been this and that" and I told them "look my sons been getting urine infection upon urine infection what was I supposed to do? Just leave him?" So I was down at the doctors all the time with him (p9, 430)</p> <p>We had John's mum and step-dad and his sister and all that was over too and it was kind of house full and they were coming and it was like, look I've got a house full of people do you have come and check up on us! (p13, 645)</p>
	Non-judgemental support	You could talk to her (mid-wife) about things, and she willnae judge you,
	Significance of feeling understood	<p>M:...I stayed in on the Monday night..eh.. and on the Monday night I was getting really bad contractions</p> <p>T:Uhuh</p> <p>M:and they just left me</p> <p>T:Uhuh</p> <p>M:the night staff was terrible</p> <p>T:Uhuh</p> <p>M:they just left me lying there in agony.(p2, 51)</p>

Feeling intruded upon by professions	Feeling crowded/suffocated	I wouldnae it would nae have bothered me to have them there as long as they didnae crowd me too much , cos that's what they done, when I had Luke, they were just there in my face all the time, and I could nae cope with it; (p8, 374) I had no life (p8, 397) And they kept coming in and out and I thought, I cannae keep doing this anymore (p9, 405)
	Relentless	B:They were in and out like yoyos. (p8, 380) So it's just one thing after another with them (p9, 452)

Appendix 13: Summary table of individual analyses

Table3: Summary of analyses of Ruth's transcript

Super-ordinate theme	Emergent theme	Excerpt from transcript (page and line number)
Challenges to building trust	Mistrusting of professionals	<p>Cos I didnae want to sleep, I just wanted to sit and stare at my baby. ..Make sure he's going to be there and em, cos, in the back of my mind, I thought maybe the baby won't be there when I wake;</p> <p>when they decided when the baby could come home, I still didnae believe it and for a couple of months after they'd said that I was still arguing with (partner) and saying that em, "it's no going to happen, it's no going to happen" I won't believe it until it actually happens until I give birth and bring the baby home, that's when I'll believe I'm allowed to keep my baby. So, all the way through my pregnancy, well, most of my pregnancy I felt that I was carrying this child and I was going to have to say hello and then good bye and so it was nae a very nice pregnancy like, the actual birth and bringing the baby home was the best part (p3, 127)</p> <p>it wasnae until after I started pushing the baby oot I felt a wee bit scared cos still in the back of my mind I felt like this baby was going to be taken away from me basically although I knew, I was told I'd be allowed to keep the baby, but there was still that fear there so. So it was like working towards letting this baby out and all of sudden letting this baby out, it was really scary. (p5, 236)</p>
	Trusting relationship with professionals	<p>as the night went on it did obviously I trusted them enough so that I could fall asleep and things like that (p6, 291)</p>

Challenges to providing support	Significance of support from family	<p>I just had everything that I needed if em if I were to be in pain or scared then I could speak to the midwives there or my mum, partner, can reassure me talk to me, make me feel comfortable (p6, 254)</p> <p>It was nice to have two close people there that mean so much to me there and to support me so that was really nice (p5, 230)</p> <p>I think it was because it was less painful, I was relaxed, em and I had my mum there and partner there, two people, at the moment that are most em are important to me (p5, 224)</p> <p>M: I think it was because I had my mum there and I had (partner) there and people that were looking after me there, made me feel relaxed so I felt good. (p5, 244)</p>
	Perceiving professional input as an intrusion	<p>(by social work) They don't really do anything, I don't ken if it's support to be honest wi you cos all they do is come in saying "hi-ya, how's you, how is baby how are things between yourselves" things like that I don't seethat as a support, cost that's just normal chitchat (pause) cos like for me, if we were stuck with money or something and they could like give us a loan of money something, that's supporting us, not actually just saying "hi-ya how's you" I don't think that's support at all (p16, 758)</p>
	Feeling supported by professionals	<p>We do things about weaning, cos obviously Ross is at the age of weaning now, so we talk about weaning, what's good for them what's bad for them and things like that, we do some cooking and things like that general discussion if we've got any worries about the baby cos obviously there's a mid-wife there and you can ask questions and things like that, sitting down having a cup of tea and a blether and things like that</p> <p>T: Yeah</p> <p>M: Swapping parenting tips and experiences, teething, how's your baby doing today. We talk about teething and general things like that about babies. It's all baby, baby, baby, which I enjoy anyway (p10, 466-476)</p> <p>M: So I just gave that a miss and continue with the young mum's group cos it's really good.</p>

		<p>T: So in what way do you feel it has made you more confident?</p> <p>M: Em I'm not as shy now, I can em, like if I don't know someone, I've got more confidence to actually speak to them rather than shy away from that person and try and engage wi them. Whereas before, if I didnae ken someone I wouldnae talk to them and I would sit in the corner and things and I'm getting much better, getting much better to socialise as well (p9, 402-410)</p> <p>It was only one midwife but she was doing most of the care for me and baby so it was really nice and she was the one who set me aside in another room and let me speak and cry and she was there. So she was really good and if I had a problem then I would speak to her also, it was good I had a nice relationship with her (p7, 308)</p> <p>I got a bit tearful and things like that and one of the midwives took me away to another room, spoke to me, gave me a shoulder to cry on. And things like that, so it was really good. It was nice that they actually did that and listened to me, let me get it all out basically (p7,300)</p>
	Willingness to engage with professionals	<p>I need to prove myself to social work I can do these things for myself and that I can work with social work (p8, 364)</p> <p>so I just thought of somebody popping in saying "hello, how are you?" em ,just like normal conversation so and then cos I thought that way it was fine, I was willing to adapt wi them, do what I was suppose to do, engage with them. (p15, 707)</p> <p>I could have my life back and be normal but at the same time I knew it was good, it was it was for a good cause, it would be that I could be a mum again, with their support it means my baby would be at home, it would nae be another child in care and having to see them once a week for so many hours and that's the sort of way I would think about it, so I was grateful if you like to even get another chance, for me this is my last chance of actually being a mum again and I didnae think that would ever happen, so it's good, that actually social work were giving me this chance to support me in what I need to be a mum (p18, 847)</p>

Coping with hospital environment	Feeling lonely in hospital	<p>I think it was just em there wasnae always someone there to keep you company that was the hardest part and being on my own em no-one to talk to well apart from the mid-wives when they had time, no having my friends or family there wi me, to keep me company, that was the hardest part (p11, 498)</p> <p>but it was lonely, I did nae like it at all, it was horrible (p11, 509)</p>
	Actively seeking support from professionals	(mid-wives) M: Just boot if the midwives had noticed I was feeling a bit down and things obviously they would speak and say we're always here if you need someone to speak to so and that's what I did
	Befriending other mothers	<p>Obviously they asked how many children did you have previously , is this your first one, what were your experiences and things like that just general chit chat and things like that and it was really nice</p> <p>Lonely cos if you dinnae speak to anyone, you do feel lonely and that's when you get quite tearful. So that's one of the things I learnt, tae be brave enough to speak to other people and it did help (p7, 335)</p>
Coping with child-care	Feelings of self-doubt	<p>I cannae, I just, I dunno I think I just couldnae believe I'd had another baby and he was mine and I was going to be a mum again, so I just wanted tae watch every moment and just be there for him, I knew I needed to sleep but I just cannae (p6, 272)</p> <p>It was strange cos obviously I had my other children had been away for so long it was like I've got this little child here, I little baby again, you've got to meet their needs and the demands of a new child and sleepless nights and coping wi all that, housework and normal day to day routines and that em it was a bit daunting for me (p13,611)</p> <p>It was just the actual fact, the children before hand and not being a mum for so long and having a new baby eh, it was a bit daunting for me, "can I actually do this? (p13, 634)</p>

	Sense of adjustment	Actually getting back into the routine of being a mum again, and following the demands of a child again, once I got used to that again em it was fine. (p13, 632)
How support was delivered	Feeling understood	Oh, I was I was I was vulnerable, I was tearful and I was like “oh no” it was scary cos I had never heard of this thing that they were going on about before, I never even knew that babies had pulses; so I learnt something new but it was scary at the same time (p12, 558) I was finding it hard to understand cos of my learning disability, so he drew on a piece of paper wi like the pulses (p12, 571)
	Feeling judged	M: I felt like I was under complete pressure that I have to say everything properly and make sure the answers were the answers they want to hear but em at the same time be truthful, be very truthful and honest em from what I know and acknowledge and that was quite hard cos I was under pressure (p3, 116) Just knowing the fact that social work would be back in my life again. That was the hardest thing. Cos you’re under so much pressure and people constantly watching you and you’ve got to do everything properly you had to get it right all the time. So that was a big stress for me. (p14,689) M: No, they did nothing with me, but I knew that when I was in there they would be taking notes and seeing how I am caring for Ross and things cos he was on the register and things so the mid-wives were more involved with me rather than other people cos he was on the register. They were taking notes to feedback to social work on how I was getting on looking after the baby on my own in hospital and caring for him and things like that. (p11, 516) I’m doing what I’m suppose to do and so that means my child’s happy and I

		<p>can give him everything he needs</p> <p>T: Yeah</p> <p>M: It's just reassurance for myself (p17, 817-821)</p> <p>I had to just keep reassuring myself that I was doing the right things and I was giving Ross what he needed (p13, 641-2)</p> <p>The staff there were really nice and they really reassured me that that wasnae going to happen that the baby would still be there when I woke up so (p6, 287)</p> <p>It makes me feel good about myself and em, I'm doing what I'm suppose to do and so that means my child's happy and I can give him everything he needs (p6, 287)</p>
	Feeling told what to do	<p>She was a bit, like she wouldnae so much support, she would be telling you what to do you should do this with the child and you shouldn't do that with your child type of thing (p17, 803)</p> <p>she'd more advise you, give you, advise you, you can do it that way, well our way, but em, I would do it that way, or no so much she would do it, just give us advice other ways we can turn, so if what we were doing wasnae right, we would take her advice on what she would tell us (p17, 806)</p>

Appendix 13: Summary table of individual analyses

Table4: Summary of analyses of Jacinta's transcript

Super-ordinate theme	Emergent theme	Excerpt from transcript (page and line number)
Significance of support from family	Value of emotion support	my mum and dad they gived us a lot of help through it T: Did they, what kind of help did they give you? M: Like inviting us down to the house, cuddling us and all that and things would get better for you and things like that. They helped us through it, my family, they were a big support in our lives.(p15, 694) I felt awfy, I felt like a labour pain coming on so I phoned my mum, mum I feel like I'm in labour, and she says you're in labour and she says your to keep breathing, and so my mum was a grand help through it (p1, 32)
	Value of practical support	But I was absolutely shattered when I had family coming in. Absolutely tired and I fell asleep. Then I fell asleep about 9 o clock and they says" I" , and I says "what?" , " Harry's here" and then I woke up and Harry was giving his daughter a feed, were n't you Harry? When I woke up at 10? In the morning, so he changed her nappy and fed her. (p7, 336)
	Managing unhelpful support	M: one time I bathed Mary when Harry was in and I was laughing you put on a nappy and put it on the wrong way round (laughing), it was funny T: Did you have to keep him right? M: Aye, I had to keep him right
Feeling supported by professionals	Feeling emotionally supported	My mid wife was there telling me to calm doon and all that through my pregnancy. She was really helpful (p3, 101)
	Value of practical support	It was it was one of the mid-wives, one of the nurses she gave me a hand and showed me what to do like bath her. (p5, 245) And so the mid-wife showed you how to M: Yes showed me how to put the water in then I just carried on and bathed her (p6, 253)
	Importance of concrete advice	Very good, good, showed us what to do and that
Coping with hospital environment	Feeling scared	A bit scared because I never had time to spend with my husband Harry cos he had to come in after work go back at night cos he was working at (place ¹⁹³ name) and I did n't have many visitors so then my mum and my dad came up

		so I was happy to see them (p5, 206-209)
	Feeling lonely	T: So am I right in thinking from, what you've said there, that it was maybe a bit lonely M: A bit lonely with no one to talk to (p5, 210)
	Befriending other mothers	but I met quite a lot eh I met this lassie who had a baby boy and it was a bit premature and she knowed my sister so I made friends there and I met another girl as well so she's a friend of mine I met in hospital she had a wee boy at the time I was there T: Ok so there was some other mothers there so did you find that helpful? M: It was helpful but at first I was really lonely because half of them went home and I had to wait until Mary got the all clear to get Mary home (p5,
Challenges to building trust	Feeling betrayed	I was absolutely tired and then and then I went back to my room and the social workers and all that was sitting and that was a shock (p3, 123) Yes they must have come to the hospital and em Harry and I didn't expect them to be there after the birth, you know, I was really upset, I told them to bog off, go away I'm tired, even the nurse involved told them to leave cos I was absolutely tired after having a child (p3, 127) Yes, Harry and I didn't expect any social work to be there and I did nae know who got the social work there, Harry and I are still quizzing, we don't know who got the social works involved. It was a shock! (p6, 275) ...there was a big investigation on up there and (social worker) came up and she went behind our backs and got a court injunction without our permission to take our child away. (p12, 593)
	Perceiving social work as a threat	M: Like saying sort of congratulations on your child and like one of them ...she was sort of looking across at my child. I says you're no taking my child away I says to myself (p6, 285) T:...you said, it was a scary thought, that they were there to take your child

		<p>away. What made you think that?</p> <p>M: I don' know, it just the thought of them being there and sort of anger inside about who got the social workers involved. It was really scary (p7, 308)</p>
	Overly-intrusive	<p>they wanted to know our private affairs and what we do with Mary and that and I didnae like that (p14, 672)</p> <p>T: What kind of things did you do there then?</p> <p>M: Bathing her and they came in every five minutes, changing her and they had to come in every five minutes, and all that. (p10, 479)</p>
Perceptions of support	Feeling judged	<p>(by nurses) Yeah, they came in the next day and there was about, there was a load of washing and they was saying that Harry and I never changed Mary and her nappy, I says what's that on the floor there's about 100 dirty nappies, there's a load there, what you trying to do, make me out to be a bad parent? (p11, 516)</p> <p>Saying things like I was nt keeping Mary clean and tidy but I says what's that on the floor, there's 25 nappies down there, they were alright (p12, 580)</p> <p>M: Just being abrupt. Saying I was n't sterilizing the bottles properly, never put them in fridge, what's that there's four bottles in there already made up. I just told them to leave (p12, 585)</p> <p>I says "get out" I know what I'm doing (p10, 491)</p> <p>Yeah to see how we got on with Mary and one time at five o'clock she was crying and so I sneaked through and put five scoops of milk in and added the water and sneaked back through and changed her nappy and all that and she (mid-wife) and she came through and said did you feed L and I says yes, Harry and I fed her until about half past five but she's away to sleep again ok I'll shut the door then (p11, 533)</p> <p>She says "(name) well done for bathing her. I've never seen you do that before (p5, 246)</p>

		<p>It's every hour I had to feed her then at five o'clock I had to feed her and change her nappy and I had to get the nurse to warm it up a wee bit and I changed her nappy and feed her and they said that I done really well. (p5, 228)</p>
	Interfering/feeling told what to do	<p>They were interfering, telling me what to do with Mary the whole time (p8, 396) Horrible to me. Telling me what to do with Mary and all that. (p12, 567)</p> <p>M: Bathing Mary and like feeding her, putting her to bed and putting clean clothes on things like that. And do her bottles and all that. T: And was there staff there? M: Yeah every five minutes, they always interfering I says "get out" I know what I'm doing (p10, 488) the social worker came and (name) and (name) came and they was bullying Harry and I to go to (place name) to do this 12 week course and then we didnae want to go and it was really hard and all that. And if you dinnae go we are going to have to take Mary there and then to foster care (p9, 414)</p>
	Significance of feeling understood	<p>I said to Harry, what's going on here? Oh, he says, I think I shook the bairn. I says what are you on about. You would nae harm her (p13, 629)</p> <p>M: He told one of the staff he shook Mary but he never.</p>
Learning how to cope	Changes in self	<p>M: My moods were ok, but sometimes when I was up at (place name), sometimes, my mood was going too high or sometimes too low. I always had arguments with Harry (15, 739)</p> <p>M: My hormones and that were going different places T: Right, so, it was quite high sometimes, in what ways were you quite high? M: A bit angry, cos I had mood swings cos its wi something to do with my hormones and all that when I was on my periods and that (p15, 743)</p>

		<p>T: Ok, was there a bit of a difference after you had her? M: Yeah, making me feel pulled down I wee bit T: Right, M: But Harry and I was really stressed out cos we just wanted to have Mary back (p16, 756)</p> <p>T: So there no staff you could talk about how you were feeling M: Na, T: No midwife or anyone for you to talk to? M: Na, I kept it inside and took it out on the dearest one (p16, 774)</p>
	Coping with child-care	<p>M: Yeah there were quite a lot of nurses going around to see if you wanted any help but it was difficult trying to get her baby gro on. It was so tiny (p6, 269)</p> <p>M: Well I was going to breast feed her but Mary didnae like it so I had to give her the bottled milk T: So what was she doing then? M: sort of like biting my nipple, she didn't take the milk, so they says try it but she did nae take it so I bottle fed her and she took the bottle of milk straight away (p5, 232)</p> <p>Well, it was supposed to be one night. But they came often cos I could nae see Mary cos, she had, she had colic Harry, and she cannae get her, cannae get her wind away and I was sort of struggling and so they came in to give me a hand cos I was up all night trying to get her wind away and I could nae get her wind away so they told me she had colic (p8, 379)</p>
	Coping with physical pain	<p>It was a bit scary you know, I never my mum never even had it when she was expecting with me at the time. Never had anything like that with me. (p2, 95)</p>

Appendix 13: Summary table of individual analyses

Table 5: Summary of analyses of Betty's transcript

Super-ordinate theme	Emergent theme	Excerpt from transcript (page and line number)
Learning how to cope	Coping with hospital environment	<p>Boring. Really boring cos after you've had a section you've got to stay in hospital for five days (p.6, 291-292)</p> <p>It was boring, I was alright cos my son was there and I kept going down to SCUBU, that's what they call it. SCUBU. We went down there, I had to feed him (p.7, 309-311)</p> <p>It was, it breaks up the day, somebody's in seeing you cos it's too long anyway, ken the days are long, if you've got someone coming in the time goes quicker, you know (p.17, 840-842)</p> <p>M: No not really, cos I dinnae ken anybody, they were all strangers (p9, 444)</p> <p>You cannae go oot. You're stuck on the same ward all day and all night. (p11, 441-442)</p>
	Coping with physical pain	<p>straight to the hospital got the bairn oot and I dinnae see my son til about half past 10 at night, cos I couldnae get out of bed, I was paralysed. I had no legs. It was horrible (p4, 187)</p>
Learning from professionals	Importance of concrete advice	<p>She showed me what to do (p7, 342)</p> <p>Cos it was my first kid you know, you want to learn and what you learnt was by watching, you know, seeing what she did (p8, 360-362)</p>
	Practical support from professionals	<p>M: So what was it she did that was helpful then?</p> <p>T: Showing me what to do and how to dress and clean him and that, you name it (p8, 356-358)</p> <p>just learnt to bath him change him put clothes on which I did. (p7, 347)</p>
Feeling cared for	Empathetic (mid-wife)	<p>and she could understand that there were problems (p7, 342)</p> <p>Yeah cos she knew what I was going through cos it was my first kid you</p>

		know, (p8, 361)
	Accessible (mid-wife)	She really understood. If I dinnae ken anything I would just ask (mid-wife) p8 (364-365)
Challenges to building trust	Trusting relationships	I think it was cos they were there for you, not behind you, there for us, put it that way (p8, 395)
	Feeling victimised	I wouldnae go out on my own, I used to take my mum out wi me for protection; cos folk said I should never had had one, "she shouldnae have a child, no her, she cannae even look after herself" ken, Yeah, well, I thought I had friends but they just knived me in the back. T: Was that after you had (name) that people did that? M: Uhuh, "What is she doing wi a bairn?", T: Right M: "She's too ugly to have a kid", "too stupid to have this kid" (p13,615) M: After I'd had (name), "What are you doing wi a kid?" "you cannae look after yourself never mind a kid" and that was hurtful, that was supposed to have been my friend. You know (p13, 638)
Significance of support from family	Importance of support from family	I had my mum wi us, she was there all the time wi us except at bed time. She was there for us. If I needed something, she would get it for us. That's what she was like. (p. 9, 411)
	Importance of practical support from family	She came and helped us and dressed him, looked after him and like (p. 10, 468-9) M: Well she had all the knowledge T: Yeah M: about what to do and all that. I done it myself, I done it a lot myself you know but she was good, she was great that way. She really was good (p10, 473-477)
	Instrumental support from family	She used to keep going out and buying toys

		<p>I had to sub off my mum and then my dad we need a long term ??for baby food. He gave it to me like.</p> <p>T: Ok,</p> <p>M: He never wanted it back, he says “here, that’s for the bairns” (p12, 565)</p>
Importance of role	Increased sense of self-worth	<p>I felt great cos I had something to prove ken to show what I had. I had a child and he was perfect. (p10, 487)</p> <p>I was fair chuffed showing him off and that “Oh what a gorgeous boy!” (p10,493)</p>
	Sense of purpose	<p>it wasnae so bad (her mood) cos I had someone to take care of (p11, 513)</p> <p>I had something to prove, I had something to look after and care for, I loved him and that’s it.</p> <p>T: So who did you feel you had something to prove to?</p> <p>M: Folk. The yins that were picking on us when we were at school. They had nae kids and I had yin.</p> <p>(p.11, 513)</p>
How support was delivered	Feeling reassured	<p>She would come and speak to you. You know. You’re doing well, you’re feeding her, you’re giving him what he needs, she was guid (p14, 704)</p>
	Sense of humour	<p>T: Yep, what was good about him?</p> <p>M: He used to make you laugh ken cheer you up, when he came round ever body smiled. He was that guid like. (p11, 539)</p>
	Feeling told what to do	<p>M: A wee woman, quite nice though but if you were nae doing things right, trouble!</p> <p>T: So what kind of things did she pick you up for?</p> <p>M: I had a bottle, cos I had a bottle cos the bairn was drinking its milk, of course, I left the bottle, what did I get “this shouldn’t be sitting here, this should be washed”, I went “he’s just finished it” “that’s no the point it should be in the kitchen in the sink”, “oh God”, nobody liked her either. (p 14, 690-697)</p>

	Feeling understood	<p>I understand her, she made it clear, as day you know; Yeah, they were good. They even explained what was happening to me when he was little cos I was at the hospital wi (name), and they had to write doon what they were going to do wi (name) and what they were nae going to do (p16, 790) they were telling me things, and I couldnae always pick up what they were saying, so they wrote it all doon so that (partner) would get it explain what so much means (p16, 802)</p> <p>T: Right ok so that's interesting, you felt you could understand her, M: And she could understand me, T: So what did she do do you think that made you understand her M: Plain. Plain how to speak how to talk, and that's what she was there (p16, 775)</p>
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Appendix 13: Summary table of individual analyses

Table 6: Summary of analyses for Donna's transcript

Super-ordinate themes	Emergent themes	Excerpt from transcript (page and line number)
Significance of support from family	Value of practical support (mum, brother & partner)	<p>But when I finally went into labour like my mum was there and stuff and she was like a big help (p1, 42)</p> <p>When I finally got hame, I stayed at my mums for the first two, three weeks and stuff to support us and I had my aunt and uncle as well (p3, 102)</p> <p>When she moved to (place name) it was a bit harder cos you couldn't just pop on a bus from (place) to here em so every time she came over she used to take the bairn away with her for a couple of days, and stuff. (p.4, 157-161)</p> <p>But at the hospital he was great. He was holding my hand and stuff like that (p8, 391)</p> <p>Then she helped my through the first night, like getting up for the feeds (p3. 99)</p> <p>she had to sleep in the chair and I had the bed so and she got up for most of the feeds (p13, 607)</p> <p>T: Good. So they showed you how to do that did they and what else did they show you?</p> <p>M: That was it, bathing and changing her. That's it, cos I never changed her first nappy, it was eh, I let her dad do that (p8, 381)</p>
	Feeling supported emotionally	<p>I was panicking obviously being a new mum and that and cos my ex could nae stay there at the time we were going oot. I had to get my mum to come back cos I did nt want to stay on my own (p2, 96)</p> <p>and then I realised I was going to be on my own at the night time so that's why I had to get my mum to come back (p8, 397)</p> <p>At hospital he was great. He was holding my hand and stuff like that (p8, 391)</p>

	Support with tiredness/managing pain	<p>That's why I wanted my mum to come back cos I just wanted to sleep (p13, 601)</p> <p>I was tired and sometimes I never heard her and that's what I was scared of just, in case I dinnae hear her (p13, 609)</p> <p>cos every time I needed a sleep or something, my mum used to take over, like Tom used to help my mum and that as well, like he used to feed the bairn as well, at that point, like, when I was sleeping and stuff even then I used to ask my brother will you watch the bairn if I go to sleep for an hour and he says aye no problem (p15, 716)</p> <p>feeding her and that, I was still in pain but I still managed to still do it, but my mum was there as well, because I was in that much pain, I had to have someone there in case I dropped her. Every time like I moved it hurt, (p3, 130-134)</p>
	Support with asserting her needs	<p>Then I got my mum to sit in one day when the mid-wife came and she sat and listened and she did admit she was wrong with what she was saying and the mid-wife turned and she said to her dinnae gie her, I cannae think of the word dinnae say she's not daein it the way you're expect her to dae it cos everybody's different, and then after that she was quite nice wi me. (p11, 543-547)</p>

	unhelpful support	<p>(brother) ..he went, he took my bairn to the pub, and I wasnae happy wi it cos she was only a couple of weeks old and em so, what I done was I wouldnae let him take her anywhere unless I was wi him(p6, 252)</p> <p>I had no control when my brother was involved (p5,202)</p> <p>em it was just like with my brother Tom, when he had her, he had to have her, nae body had a say basically (p5, 245)</p> <p>(by partner) cos I wouldnae let Jon bath her cos when Jon bathed her one time, he made the water far too hot, and when he pulled the bairn out of the bath she was all red and he burnt her so I had to buy some cream for the burns and stuff and then I still, for quite a bit I wouldnae let him do nought with the bairn cos of that (p10, 494)</p> <p>but I told Jon you need to get rid of that dog cos I cannae even go near my bairn cos of that dog. He was like I'm no getting rid of the dog (p10, 474)</p>
How support was delivered	Feeling told what to do	<p>They were telling me stuff to dae and how to dae it and I was getting quite snappy wi them, cos I was like, have you got kids of your own, no, well don't tell me what to dae then (p11,516)</p> <p>then it's just I wanted to bring up my bairn the way I wanted to bring her up no somebody telling me with no kids telling me how to bring my bairn up (p18, 860)</p> <p>I started doing more things the way I was doing it, the way I wanted to do it, the way I was telling everybody this is how it's going to happen, and if you don't like it tough even though people were nae happy wi what I was doing and stuff (p12, 549)</p>
	Feeling judged	<p>I was changing her bum there and I put the nappy at the sink cos it was a dirty nappy and I was putting the thingy on and like I left the bairn cos obviously she's not going to move and stuff and I left the bairn lying there and I went and got one of those nappy like things and she went "you never done that right" "you shouldnae have left her on the floor" I was like "she aint going to move for crying oot loud" and I chucked her oot my hoose (p16, 771-778)</p>

		<p>Like certain things like dressing, certain ways I would like feed her, and wind her, they said I was winding her wrong, I was hitting her back too hard, or I wasnae doing it hard enough and but I didnae want to break my bairns back and everything like that (p. 12, 554)</p> <p>cos they were coming in and saying I wasnae doing it right when I was and stuff (p11,538)</p>
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<p>Learning how to cope</p>	<p>Coping with child-care</p>	<p>I was panicking obviously being a new mum and that (p2, 96) It's just like, becoming a mum, you sometimes, think "am I a good mum?", "am I going to be a good mum?" or whatever stuff like that, that's what I mean by weird (p7, 345) Aye, mainly nervous, "oh am I going to be doing this right?" and stuff like that cos they have to show you how to bath them in the hospital and I got to dae it and I was shaking and that (p8, 351) She just came along to show me how to bath and things. Like I wouldnae change her bum, like for the first, until that thing falls off the belly, you know where you cut the cord, like I wouldnae change her bum until that had fell off T: Why was that M: Cos I was scared that I was going to hurt her but then I did try it and I was taking too long you've got to be quick cos they can start, getting fed up basically so I had to try and learn how to do it faster (p8, 368)</p> <p>We went hame like put her in her moses basket and stuff and then she woke up and needed her bum changed and em Jon was changing her bum and I was in the kitchen doing something and he shouted me but it was more like a scream and he was panicking cos she was choking on her mucus and she was going purple, and I screamed, I had her upside doon and everything and I got my mum?? and I said mum she's not moving and I was greeting and everything I had her upside doon, like I dinnae have her by her legs it was like that, under my arm and nothing was working and all of a sudden she was alright, I took her to the doctors the next again day to make sure she was alright (p9,426-436)</p> <p>Sometimes I never heard her and that's what I was scared of just, in case I dinnae hear her, but then when I got back, when I got out of hospital it just came naturally and I woke up every time she woke up and sometimes I woke up before she woke up cos I got into a routine so it was quite good. (p13, 611)</p>
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	Changes in self	<p>M:I did think I was getting postnatal depression. T: Yeah? M: Aye cos I was sort of pushing her away when I came back here. T: So after you'd been at your mums, back here M: Yeah, and Jon had to get the mid-wife to come out cos he was seeing a change in me. And he was looking after the bairn most of the time.</p> <p>I felt like I wasnae daeing things the way I should be and that. I felt like a bad mum so I kind of detached myself sort of thing I would be upstairs sleeping or going out for a walk without her I used to go fro a walk all the time, I used to talk the dog a walk without the bairn. (p14, 656)</p> <p>Then they got doon to the bottom of it they found out I was like scared. Like to be, to get involved, like I don't know what they called it, but they says it was nae postnatal depression cos it kept going after they been out and they kept coming oot and they were saying that there was no interaction with the bairn (p13, 628)</p> <p>T: What made them think it was nt postnatal depression? M: I dunno, they just said it was more, cos I was doing stuff with her cos they said, you wouldnae even want to look at her or whatever and I was taking time to go over pick her up, giving her cuddles, and then changing her bum and giving her baths (p14, 684) cos like, sometimes, I didnae want to hold her, I would just leave her in her bouncy seat thing which I dinnae feel was like a problem cos I dinnae want to hold her 24 7 so she got used to getting picked up and that's what I explained to them cos Jon used to hold her all the time, and then he went to work she wanted picked up by me all the time so I just let her scream in her bouncy chair thing and they says that's fine cos it's no going to harm her to have her greet as long as she's no greeting hours on end. I was like she wasnae greeting for hours on end and I just stuck her dummy in her mouth and she shut up that was it or give her her bottle and then she fell asleep</p>
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		(p14, 688-698)
Ambivalence towards support from professionals	Perceiving professional input as an intrusion	my mum was a big support in my life, but the rest of them was just getting on my nerves basically (p12, 562) So basically that's why I came back early here, to get away from them all (p12, 559)
	Importance of practical advice(health visitor)	Most of the things that she was doing with the bairn was helpful but when she was asking me questions and stuff like I gave her truthful answers and stuff and sometimes I said I wasnae coping and she was like right get yourself oot walking and stuff and that I did do. She was quite helpful that way (p18, 856) I only have to do something once and then I ken how to dae it but the thing is I knew how to change babies bum but whatever and stuff but it was different with (name)cos she was cold you had to have the water a certain temperature for the bairn for a couple of months or something and I dinnae mind them coming in and daein that cos that was important (p11,523)

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Original Articles, Review Articles, Brief Reports, Book Reviews and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

5. MANUSCRIPT FORMAT AND STRUCTURE

5.1 Format

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- Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
- McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
- Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

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